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Marginal Men: Men with breast cancer negotiating gender

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Abstract

Breast cancer is a global phenomenon and each year charities and organisations encourage people to become involved with Breast Cancer Awareness Month. Around 50,000 women and 400 men are diagnosed in the UK each year. This research explores how men experience being a breast cancer patient, and how these are to be understood given the positioning of breast cancer as a disease of women. Breast cancer's pink ribbon culture is ideal for exploring the relationship between gender and illness, showing the mechanisms through which men are less able to participate in this community.

Bury's concept of biographical disruption is not applicable for men diagnosed with breast cancer, as they enter a world which is fundamentally contradictory. It is appropriate to use Park's theory of the marginal man, a man in two cultures yet not fully assimilated into either. The marginal man has a double consciousness, occupying a privileged position. This idea of marginality follows throughout the Chicago School. Star develops marginality to include objects and events, showing standards can become rigid and produce exclusion. Marginal men are able to see beyond this rigidity.

Three datasets were analysed using a discourse analytical approach. Findings showed breast cancer challenges hegemonic masculinity as men are marginalised. Gendered assumptions regarding the pink ribbon and ideas of masculinity and femininity influenced the extent to which individuals became involved with this community and how this was (not) accepted by others. The split between gender and illness resulted in people seen as their gender identity first rather than their illness identity. The awareness of breast cancer is linked to hegemonic femininity and reinforces hegemonic masculinity, as institutions construct awareness, and charities see awareness as gendered. This reproduces normative assumptions about masculinity and femininity and is firmly linked with breast cancer. Recommendations for broadening this research are suggested.

**Marginal Men: Men with breast cancer
negotiating gender**

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A thesis submitted in fulfilment of the
requirements for the degree of Doctor of
Philosophy

School of Applied Social Sciences

Durham University

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Declaration

I declare that this is my own work and has not been submitted for the award of a higher degree anywhere else.

Statement of copyright

The copyright of this thesis rests with the author. No quotation from it should be published without the author's prior written consent and information derived from it should be acknowledged.

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Introduction

On the 1st October 2012 Buckingham Palace, the Tower of London and Nelson's Column were lit up with pink light. Other landmarks joining them on various dates throughout this month were the Empire State Building in New York, the CN Tower in Toronto, the Palace of Culture and Science in Warsaw, the Tokyo Sky Tree, the National Science Centre in Kuala Lumpur, the Sky Tower in Auckland, New Zealand, Christ the Redeemer statue in Rio de Janeiro, and the Nelson Mandela Bridge in Johannesburg. All of this global activity was done to raise awareness of breast cancer.

Breast Cancer Awareness¹ Month (BCAM) aims to increase the awareness of, and support for, the early detection and treatment of breast cancer, as well as palliative care, according to the World Health Organisation website, which also states breast cancer is the most common cancer in women worldwide. According to the American website for National Breast Cancer Awareness Month (NBCAM) (www.nbcam.org), it is a collaboration of various organisations and agencies to promote awareness of breast cancer, share information and to provide more access to services. There is a recognition that many advances in treatment and awareness have been made with regards to breast cancer, but much more remains to be done. NBCAM is, according to its website, 'dedicated to educating and *empowering women* to take care of their own breast health' (emphasis mine).

The UK charity CoppaFeel! (www.coppafeel.org) was founded in 2008 and aims to have all breast cancers diagnosed at an early stage (when treatments are likely to be more effective). The charity's founder was diagnosed with breast cancer at the age of 24, and in line with this, CoppaFeel! focuses on educating 18-30 year olds about how to check their 'boobs', and to do so regularly. The website also offers a sign-up system so that people can be emailed a monthly reminder to check themselves. The focus of the charity is on awareness rather than fundraising, and the charity reaches its target audience at festivals and on university campuses, where Boob Team

¹ This is the name currently used, although there is a call for it to be renamed Breast Cancer Action Month by charities such as the UK's Breast Cancer Campaign, to focus on turning awareness into action.

members help to spread the message about conducting regular breast checks, enabling women to become aware of what is 'normal' for them, so they can more swiftly spot if anything changes or is different. In the summer of 2013, CoppaFeel! visited more than ten UK music festivals. Festifeel, the festivals event, is a growing annual event and Fearne Cotton (television and radio presenter) has been the charity's patron since March 2011, showing the continuity of breast cancer campaigns, and reaching out to the young demographic targeted by the charity. CoppaFeel! says its campaigns are life savers, not fundraisers: a new initiative begun in 2013, known as #BraHijack, has put labels saying 'checking your boobs could save your life' next to the laundry care labels in bras, with two companies planning on launching bras containing these labels in 2014. The use of the hashtag in the name of the initiative reflects the young target audience of the charity, and draws upon the use of social media as a way of getting campaign messages quickly disseminated.

Famous people are often ambassadors for a campaign, being in a position to reach a high number of people through their work. Television presenter Lorraine Kelly through her ITV show *Lorraine* in October 2013 was encouraging women to donate their unwanted bras in designated collection areas: these bras will be recycled and sent to developing countries in Africa. The charity Against Breast Cancer will receive £1,000 for every tonne collected. The Against Breast Cancer website (www.againstbreastcancer.org) suggests additional ways to get involved, such as sporting events, volunteering, recycling schemes, and purchasing pink ribbon branded products available in their online shop.

A new idea for 2013 embracing social media is #mamming. The homepage (www.thisismamming.com) explains that '#mamming is about embracing the awkwardness of mammograms'. To participate in #mamming, people are encouraged to lay their breasts (clothed) on to a surface, such as a table or bench. It is portrayed as a way for everyone to show solidarity with all the women getting mammograms this BCAM (the procedure of having a mammogram involves the person's breasts being laid on the flat surface of the machine). Whilst it may be awkward, a mammogram could save a woman's life as breast cancer is more likely to be beaten if caught early. Men can participate in #mamming too, but they need to be more creative!

The idea is to get women ‘mamming’ where it matters, at the doctor’s surgery. Photos which have been uploaded on to Twitter and Instagram include people #mamming on tables, a piano, and a bowl of apples.

On 4th October 2013 the Asda Belfast Shore Road store was lit up pink to signal the launch of their Tickled Pink breast cancer awareness campaign, with donations from the campaign benefitting two charities, Breast Cancer Care and Breast Cancer Campaign. There is a counter on the website (www.yourasda.com/ticked-pink) showing how much money has been raised so far this year through this particular campaign. As of 16th October 2013, this total stood at £1,852,581. Tickled Pink is now in its 17th year, and over the last 16 years over £30m has been raised for the two charities. Celebrities such as singer and Breast Cancer Care ambassador Alexandra Burke, and actress Michelle Keegan (the face of the 2013 campaign) are supporting the campaign. Tickled Pink products such as tshirts, lingerie, and jewellery featuring limited edition designs and the pink ribbon are available from the website as well as in Asda stores.

The Breast Cancer Care fashion show, *The Show*, marks the beginning of breast cancer awareness month, and all its models have received a breast cancer diagnosis. In 2013, 21 women were modelling, and one man. Well-known stylist Hilary Alexander and professional teams from London Fashion Week were involved, along with patrons Denise Lewis (Olympic athlete) and Edith Bowman (radio presenter), and presenter Joe McElderry. According to the Wear It Pink website (www.wearitpink.org) from Breast Cancer Campaign, 12,000 women die from breast cancer and 50,000 more are diagnosed with the illness every year. Breast Cancer Campaign gives necessary funding to areas with the highest potential for real impact. People were encouraged to wear something pink on 25th October 2013 and donate £2 to the charity for doing so. This is an annual event which in 2012 raised £2.1m, and the ten year total for the event as a whole is around £22m.

The Great Pink Bake Off (www.pinkbakeoff.org) was a brand new initiative for 2013 for fundraising on behalf of Breakthrough Breast Cancer. Friday 18th October was designated Great Pink Bake Off day and people were encouraged to get together with their friends or, colleagues to make cakes and give a donation in order to participate in a Bake Off event. Jane Asher,

the baking expert, is the ambassador for the event and participants are encouraged to create events on Facebook, and use the hashtag #GreatPinkBakeOff on Twitter. On Saturday 19th October 2013 Oregon Ducks American football team wore a pink-themed uniform in their game against Washington State, in order to mark BCAM. Some of the helmets worn during the game were auctioned off, with the money raised going to Kay Yow Cancer Fund, which aims to eradicate women's cancers. One of the slogans used in the publicity is 'real men wear pink', emphasising how men can get involved with BCAM as well as women.

On Monday 28th October 2013 the Pink Ribbon Breakfast in Australia (www.canceraustralia.gov.au) on the national Pink Ribbon Day will celebrate the achievements and advances in breast cancer research over the past twenty years, whilst looking to what can hopefully be achieved in the future. In New Zealand, the New Zealand Breast Cancer Foundation (www.nzbcf.org.nz) has been encouraging people to get involved in order 'to help the seven women a day diagnosed with breast cancer in New Zealand'. The 5th October saw the Estee Lauder Pink Walk in Auckland, a five or ten kilometre sponsored walk in the city. On the 11th and 12th of October volunteers were out for the Pink Ribbon Street Appeal, collecting money for the Foundation and raising awareness. Alongside these specific events, on any day in October companies can be Pink For A Day and encourage their staff to wear pink in return for a donation to the Foundation. Whilst the first two events mentioned focus on individuals, the Pink For A Day campaign is marketed partly as a way to encourage greater corporate social responsibility from organisations.

The Breast Cancer Foundation Singapore (www.bcf.org.sig) was set up in 1997 with the aim of eradicating breast cancer as a life-threatening disease, with a focus on awareness and education, and regular screening. It has a Men's Support League 'to emphasise men's roles in society's fight against this affliction'. On 28th September 2013 there was a Pink Ribbon Walk (www.pinkribbonsingapore.com) to allow people to walk for the women in their lives.

Monday 22nd October 2012 was Australia's Breast Cancer Day, a day in which 'all Australians can come together to show their support for women

with breast cancer and their families' (www.bcna.org.au). The 'I Heart Pink' campaign, which supports pink ribbon day in Australia is there to raise awareness of breast cancer and to support all women diagnosed with breast and gynaecological cancers. The use of pink is consistent across countries and cultures, and utilised in a variety of ways. Pink Hijab Day has three aims, to encourage people to ask about the hijab and what it means to Muslim women; to encourage Muslim women to participate in various community projects, such as finding a cure for breast cancer; and to raise funds for cancer research whilst encouraging people to look after their health. On this day, pink is used as a symbolic message of taking action.

The colour pink features in and on many products produced especially for campaigns during BCAM, as well as being on products which are adapted in some way to be pink during October. An article published on the American Teen Vogue website in August 2012 had a slideshow with pink products linked with BCAM. Products included pink nail polish, pink jewellery, gold jewellery with the pink ribbon symbol, more pink make up, pink clothing and pink accessories. In September 2012 the Marie Claire UK website had its pick of the best beauty and fashion products in support of BCAM and these too included pink clothing and underwear, pink make up, a pink baking set, and products featuring the logo of a breast cancer charity.

In 2013, Breast Cancer Care's website (breastcancercare.org.uk) contained links to its partners who were donating money to the charity from the selling of certain items. These included 5p per pack of Smint Strawberry sweets, £1 from lingerie items from Boud Avenue, and 30p per bottle of Palmer's Cocoa Butter Formula Breast Cancer Care lotion. Throughout October, many magazines have pages dedicated to the range of products available which support breast cancer organisation. As Sarah Barclay, the beauty editor for The Mail on Sunday's YOU magazine supplement, suggests to her (predominantly female) readers: 'Crush on all things blush – the season's standout shade – and help support breast cancer awareness' (06/10/2013).

BCAM is very much a global phenomenon, as illustrated by iconic buildings and structures around the world being lit up with pink lights. As a phenomenon it is on a scale that is unmatched by other social movements built around a disease or illness condition. There is a myriad of ways in

which charities and organisations from different countries encourage and entice individuals, groups, schools, colleagues and companies to become involved with BCAM, from buying pink merchandise, to baking cakes, to participating in sporting events, to modelling, to corporate social responsibility.

All of these events and fundraising and awareness-raising activities are significant as they position breast cancer as a disease for women, with a community men can become involved in as supporters. Many of the events have a focus on empowering women, shown through the participation of women joining together with other women to raise awareness of breast cancer. By organising campaigns which only women can be a part of (such as donating old bras, and manufacturers putting awareness messages next to care labels in new bras), this strengthens the idea of a sisterhood, and women working together for a common purpose. Purchasing pink products, especially products designed for women such as make up and jewellery again shows the dominance of women in this community.

BCAM – where do men fit in?

All these major public events, smaller events in workspaces, offices and school, as well as charity-affiliated pink feminine products such as make up and jewellery for sale, and campaigns encouraging women to learn how to check their breasts and to do so regularly, position breast cancer as an internationally-recognised disease of women, a disease for which awareness and funds need to be raised in order to provide support for women diagnosed with the disease, as well as their family and friends who will be supporting them. Breast cancer is also seen as a disease which can affect all manner of women, all across the world, as shown through the internationally-recognisable buildings and structures being lit up pink in October across the years.

BCAM is generally seen as a positive series of events with which to get involved. Businesses and organisations are encouraged to participate, perhaps by sponsoring an event or donating prizes (especially high-value prizes) to an auction, as part of their corporate social responsibility. It is

suggested that events such as dressing in pink for the day, or having a pink cake baking competition, could be done at work with a group of colleagues, again highlighting to employers that raising money for and awareness of breast cancer is a beneficial use of their employees' time and resources, as well as having the potential to be fun and entertaining.

Whilst BCAM is seen as positive from a business perspective point of view, the overall feel and look of BCAM as a whole is also seen as happy and positive. The dominance of pink, which is usually viewed as a happy and cheerful colour, adds a sense of light-heartedness to events, and helps such events to be visually appealing as well as clearly identifying with the overall 'brand' of BCAM even if events are being organised on behalf of different charities or organisations. The plethora of pink beauty products available throughout October each year add to a sense of occasion, of dressing up perhaps a little differently from usual, or adding an extra touch of femininity. Events such as baking competitions are also seen as being fun and positive: whilst it may in name be a competition, the emphasis is on getting together with friends or colleagues and socialising over a slice of cake all in the name of raising funds for breast cancer charities.

Other events during BCAM are positive in their outlook and celebration of how much has already been achieved. The Pink Ribbon Breakfast in Australia was a celebration of how much money had already been raised, whilst looking to how much work could be achieved in the future. The Breast Cancer Care fashion show featuring people who had received a breast cancer diagnosis modelling for the first time celebrates how far these individuals have come on their journey as well as demonstrating how breast cancer does not automatically need to mean an end to ideas of femininity, of beauty and make up, of taking pride in one's appearance. Such events are also usually expensive to attend with tickets limited, encouraging people to dress up beautifully and therefore adding a sense of occasion to the event.

A positive and light-hearted approach is seen in campaigns such as the work of CoppaFeel!'s 'Boob Team' encouraging people to check their breasts. The use of the slang term 'boob' slightly removes people's 'boobs' from the medicalization associated with 'breast cancer' and fits with the young, fun attitude of the festivals they attend and the demographic of the students at

the university campuses on which they also work. Whilst they are highlighting the benefit of early detection of breast cancer in terms of successful outcomes for patients, this is done in a way which arguably is more accessible for their young 18-30 target group.

By portraying breast cancer as a female illness, there are assumptions and behaviours associated with this. It has come almost to be seen as a celebration of femininity. Women are encouraged to come together to engage in activities, usually with a pink colour scheme, in order to raise awareness for a disease that affects 'them' as a social group, despite an individual's likelihood of developing the disease themselves. One charity says on its website 'when breast cancer and its treatment overshadow everything, we see the woman underneath' (breastcancercare.org.uk), firmly placing breast cancer as a disease of women. In turn, men are also encouraged to engage in these activities, in order to help assist their female relatives and friends in what is often seen as their campaign.

A criticism of BCAM in general is that it is this positive attitude and almost light-hearted approach which can be seen as possibly detrimental to the breast cancer cause, and even upset those who are living with the disease. As the statistics published by the charities show, many women are being diagnosed with the disease each year, and despite the advances made in detection and treatment, a large number of women are dying from breast cancer each year. This is a serious situation, one from which the fun, frivolous events may detract. Pink glittery nail polish, pink cakes, and wearing a pink t-shirt at work reflect a fun, feminine nature, and does not explore the negative consequences of breast cancer, such as the impact of treatments, the consequences of these treatments, and other negative experiences those diagnosed with breast cancer may have, especially for those individuals who may have a later stage of the disease, or secondary breast cancer, which is much harder to treat and treatments may only be palliative. Similarly, many of the events advertised and organised, and the pink products or pink ribbon branded products on sale are aimed at a young, female, target audience, whereas breast cancer is much more commonly diagnosed in post-menopausal women. Many of the celebrities involved in breast cancer campaigns are also relatively young themselves. Another aspect is that BCAM reflects ideas of femininity which are based on a

foundation of being pink and 'girly', as represented by the pink ribbon, and shown through the wide array of specially produced pink objects, and other items which change to pink in October. Whilst admittedly it would be incredibly difficult to produce one symbol by which everyone affected by a disease could be equally represented, the pink ribbon for breast cancer does reflect an idea of femininity to which a number of people may be less able to relate, for example gay women who do not fit into the confines of a woman diagnosed with breast cancer, with her male partner being her support.

Alongside this, what is rarely mentioned in any aspect of BCAM is that men can also be diagnosed with breast cancer. On the website of the World Health Organisation where it states breast cancer is the most common cancer in women worldwide, there is not a single mention of it being found in men, despite around 400 men in the UK alone being diagnosed with the disease each year. The BCAM section of the website for Breast Cancer Network Australia says around 14,000 women and 105 men are diagnosed in the country with breast cancer each year, but this is the only mention men receive in this section. Generally on breast cancer websites, and in associated literature and at events, any references to men are made in relation to fundraising, and also in terms of the support men can give to their (female) friends and family members with the disease. Attention is rarely given to men who are breast cancer patients or survivors themselves. Admittedly, the number of men per year diagnosed with breast cancer, compared with the number of women, is very small, but it is not insignificant, and it ought not to be assumed that their experiences will automatically reflect those of women in a similar situation. In line with this, women are not 'only' to be seen as sufferers, or as support for their female friends and family, some women will be emotionally close to a man diagnosed with breast cancer and therefore they form another small demographic within the breast cancer community. It is not simply a case of men being in one group, and women another.

What is apparent from the discussions above regarding BCAM, its associated campaigns and the global social movement that it has become, is that breast cancer is seen very much as a disease of women, it is a disease which has been normalised as such, and positioned in a way enabling people

to come together in its name to almost celebrate femininity, what it means to be a woman, and how as part of a global sisterhood, women as a whole are encouraged to embrace this central idea of femininity and use it to raise awareness and funds. It is a culture which is dominant in many countries across the world, with its own unique branding and easily identifiable affiliated products, even though the pink ribbon does not belong solely to one charity or organisation, and is in use by many distinct separate charities, reflecting different aspects of the wider breast cancer community and the people it affects.

It is within this international, well-established and successful culture that men diagnosed with breast cancer unexpectedly find themselves. Whilst no women expect to find themselves diagnosed with breast cancer either, for them it is a diagnosis less unexpected, given the success and publicity of awareness campaigns. For men, the lack of knowledge about the disease in men means that their diagnosis is even more unexpected. Given this dominant culture surrounding the breast cancer community as a whole, how are we to understand men's experiences of being a breast cancer patient?

How do men experience being a breast cancer patient, and how is this to be understood?

This dominant feminised, pink ribbon culture surrounding breast cancer is an exemplar of how gender and illness are entangled, and how hard it is to separate one from the other. Whilst many illnesses have an associated colour of ribbon, arguably the pink ribbon is the one that is most identifiable across an international platform, especially as so many other colours are affiliated with more than one illness. Similarly, it is well-known that October has been designated Breast Cancer Awareness Month, and there is so much publicity and awareness surrounding this as shown earlier in this chapter, yet, for example, it is arguably less well-known that October is also Pregnancy and Infant Loss Awareness Month, as declared by President Ronald Reagan in 1988, a month with its own events, and own ribbon (www.october15th.com). As such, given its unique positioning, breast cancer can be used as a case study for exploring this entanglement of gender and illness, as it has created for itself a leading placement in the fundraising and awareness calendar.

Men diagnosed with breast cancer find themselves involved with this dominant breast cancer culture in a way that perhaps they had never envisaged. As with life-changing events more generally, issues surrounding identity are likely to have an effect, as individuals may need to reconsider certain lifestyles or choices or future plans. Men with breast cancer are a significant example of this, as they find themselves facing a future considerably differently than what they had imagined, with cultural references, norms and values they may not understand, or be able to relate to. It is these cultural norms, values and assumptions which underpin the identity issues men will face immediately following their diagnosis of breast cancer. Therefore, in order to understand men's experiences of breast cancer within this culture, it is crucial to explore what these cultural assumptions are, and how they impact upon the wider breast cancer community as a whole.

Following their diagnosis, men are involved in a culture which is strongly affiliated with women, to the extent that men are seen as unusual and almost an anomaly. Men are positioned as being different to the majority of women within the culture. Assuming that men make their diagnosis known to others, then these people will have their own views and opinions regarding how this man is going to experience breast cancer given this dominant community already present. As such, to understand the experiences of men diagnosed with breast cancer, it is not simply a case of researching the story of individual male patients and their diagnosis in isolation, it is necessary to research their story and their personal experiences in related to their new social position, and how they try to fit into the new social world in which they have unceremoniously found themselves. Given that breast cancer is so closely entwined with its wider community, the experiences of men with breast cancer cannot be properly considered without understanding the social world of the breast cancer community. Both men and women diagnosed with breast cancer, or any disease, will have their own set of unique experiences, but for breast cancer especially, it is very hard to consider these in isolation. By exploring and understanding the experiences of men, a minority group, within the breast cancer culture and its majority group of women, these men and their experiences can act as a window into this particular culture, and its social

norms and values. As such, breast cancer is a case study, and men the specific part of this, for helping to develop an understanding as to how social worlds are built, constructed, and maintained, focusing on this dominant, international, breast cancer culture. To understand individual experiences, there needs to be a broader understanding of cultural norms, as it is not just about individual men's first hand experiences, but the cultural discourses which shape these experiences for the individual.

Outline of thesis

The aim of this thesis is to explore how we are to understand men's experiences of breast cancer within the culture of the pink ribbon and the positioning of the disease as a disease of women, which places men in a position of being supporters and carers, rather than potentially patients themselves. Cultural assumptions can underpin men's experiences of breast cancer, and their identity issues, so it is these cultural assumptions which need to be examined. Breast cancer culture is ideal for use as a case study for exploring the relationship between gender and illness, and men with breast cancer form a specific case study for this.

The first chapter positions qualitative research as suitable for exploring gender influences on health, defining gender as a social construction and how this relates to health and illness, as well as in turn how elements of femininity and masculinity are reflected in the health behaviours of women and men. Focus is given to West and Zimmerman's (1987) work on 'doing gender' in which gender is seen as an accomplishment. Individuals 'do' their gender, and others interpret these actions in social situations as belonging to one gender or the other. The work of Connell (1995) reflects a plurality of masculinities within society, but only one can be seen as occupying the hegemonic position. Not all men may embody this, but all are placed in relation to it. Wider gender norms of society need to be understood in order for individuals to perceive an action as masculine or feminine. Considering this, it is seen as natural that women should develop breast cancer, as they have breasts, although not every woman will be diagnosed with the disease. In line with this, breast cancer campaigns have evolved over time and so reflect current cultural assumptions.

Consequently, breast cancer is demonstrated as being a female illness, and to understand this there is the need to understand the relationship between gender and health. There is a lack of information on breast cancer in men, and male patients often find themselves positioned as having a 'woman's disease'. There is a lack of public knowledge and men may need to focus on aspects of hegemonic masculinity, such as being strong, in order to defend their masculinity against the threat breast cancer poses. It needs to be considered how they maintain and legitimate their masculinity. Breast cancer is explored in terms of being a health social movement.

This leads in to chapter two, which positions men diagnosed with breast cancer as forming part of a marginal group. Simmel's concept of the stranger is used to show how an individual can be a member of a given system, but not be strongly attached. As such, the stranger can be objective, and so men with breast cancer are able to illuminate the breast cancer social world as a whole. Park termed this 'double vision' as people can see and are aware of their marginal position, and yet at the same time can see and in many ways understand the viewpoint of the majority. Bury's (1982) concept of biographical disruption is outlined, and posited as one way of explaining how people are able to rearrange their identity and lives following diagnosis of a chronic illness condition, but this theory is less applicable to men diagnosed with breast cancer as there is not the relevant guidance readily available to help them. Women have this information and guidance, but men do not. Men find themselves in a world which is fundamentally contradictory, as they are so different from the assumed norm. It is because of this fundamental contradiction that the 'marginal man' theory of Park (1928) is of use in exploring the experiences of men diagnosed with breast cancer. Stonequist (1961/1937) positioned immigrants on the margins of two cultures, but not full members of either. Hughes (1945) developed the idea of status dilemmas, and how there are traits and characteristics associated with a given status: in relation to men diagnosed with breast cancer, they are in many respects at odds with the traits associated with the 'breast cancer patient'. This leads into Strauss and the theory of social worlds, how certain processes are found in a phenomenon, and how there are rules and expectations, and individuals find themselves with multiple identifications as everyone is involved in a plurality of social worlds. There is a question as to how people share the

legitimacy of being equal members of a given community. Finally, Star (1991) is explored in terms of the unexpected nature of minority groups, and how specific systems are usually unable to cope with what is presented to them as unusual. To understand the experiences of men diagnosed with breast cancer it is not just about researching their specific experiences as individual men, it is more about the wider social worlds, and how strangers, through the idea of the marginal man, are able to be key informants in terms of helping to develop a deeper understanding of how these social worlds are built, constructed, and maintained.

The methodology chapter explains the approach taken to conducting this research. Three datasets were used: interviews with men who had received a breast cancer diagnosis, and with staff members at a national UK breast cancer charity, threads on online forums based on charity websites in the UK and USA, and a Factiva search for English-language newspaper articles referring to 'male breast cancer'. These three datasets were analysed using a discourse analysis approach. These first three chapters are intended to provide a sufficient foundation on which to build the empirical stage of the research, and its analysis.

Chapters four, five, six and seven form the empirical chapters of this research. Chapter four focuses on the concept of hegemonic masculinity, and how breast cancer in men can be seen as a challenge to this. Using results from all three elements of the dataset, the experiences of men are explored, in relation to their diagnosis of breast cancer, and their subsequent treatment and entry into the breast cancer community. Alongside this ideas of masculinity are raised and explored in terms of how masculinity is considered as a concept, and how breast cancer is very much positioned as a woman's disease that had little relation to the experiences of men. Following on from this, experiences of engagement with medical professionals are discussed, how patients felt they were perceived and treated throughout the medicalised part of their breast cancer journey.

Chapter five shows how men with breast cancer negotiate their identity in the wider breast cancer community. Men's individual experiences are presented, in order to use them to act as a window on to this wider community. There is an evident tension between an individual's gender

identity and their illness identity, and how men had to in many ways struggle to maintain their sense of identity as a man, and yet incorporate their diagnosis into their biography. As part of this illness identity, the assumption of medical knowledge was investigated, showing how a certain amount of knowledge is required in order to pass as having a breast cancer identity and being able to participate as fully as possible within the breast cancer community. In line with these ideas of identity, ideas of masculinity and femininity were explored, how people defined them and how these ideas were portrayed by both male and female patients, as well as their family and friends, and charity workers. These ideas impacted upon how people viewed their identity, how it was viewed by others, and how it was perceived to be viewed by others, and in turn this identity management linked back to involvement, and the extent to which individuals were willing to become involved with the wider breast cancer community.

Chapter six explores how men diagnosed with breast cancer fit, or rather do not fit, within the pink ribbon culture affiliated with BCAM. The three datasets reflected a diverse set of opinions, beliefs, and contradictions in how men viewed the pink ribbon culture, but also how it was perceived by women also. The use of the colour pink is explored, and the issue of pinkification, with arguably the use of such a positive, feminine colour detracting from the seriousness of breast cancer and potentially alienating both men and women who could benefit from certain aspects of the community and fundraising and awareness as a whole. The pink ribbon culture has within it assumed gendered identities, how women and men should act and behave within it, with designated roles as patients and supporters. Men diagnosed with breast cancer have to overcome their marginal position in order to be accepted as a patient themselves, and not just there in a role to support women. These gendered assumptions are reflected in behaviour stemming from gender identities in the pink ribbon culture, both in terms of how people behave, and how charities and event organisers expect them to behave.

Chapter seven focuses on how awareness and lack of awareness of breast cancer are linked to hegemonic femininity and how they reinforce hegemonic masculinity. Awareness does not exist in and of itself, it is constructed through social interactions of individuals. Regarding health

care institutions, lack of awareness can impact upon the type and quality of information and care given and received. Awareness raising is not value free, and knowledge is disseminated about a specific disease and the specific ways in which that disease is viewed. It is acknowledged that more people need to know about breast cancer in men, but it is not clear who should be leading this. Raising awareness in the future may need an understanding of marginality, and utilising their viewpoint, which has the possibility of helping all marginal groups. Gendered assumptions are shown to reproduce the normative assumptions of femininity and masculinity, and how these are linked to breast cancer, which in turn related to gendered assumptions, and gendered support. These are shown to shape men's experiences of breast cancer, in terms of how men balance their breast cancer diagnosis alongside the conceptualisation of masculinity held by both themselves and others. As a whole, this thesis aims to explore how men experience being a breast cancer patient, and how these experiences are to be understood, by showing the mechanism through which men are less able to participate within the wider breast cancer community.

Chapter One

Gender, health and illness

Introduction

Qualitative researchers are suitably positioned to examine possible gender influences in the health and illness experiences of men's and women's health (Bottorff et al, 2012). Defining gender as a social construct, it then relates to health in terms of how elements of femininity and masculinity are reflected in the health practices of individuals. Gender is seen as plural (with masculinities and femininities), specific to the context and changes over time. These authors highlighted some gaps in the literature when they conducted a search on abstracts and key words. Only four articles included 'feminine' or 'femininity(s)' in the abstract or key words: two were on breast cancer, framing and criticising femininity in context of ideal aesthetics of female body. Most research in the UK was first-person accounts, so there was not much attention to dynamics, whereas research has shown that gender relations can influence health. There was a lack of articles in which researchers considered constructions of femininity and masculinity in relation to health and illness. Many researchers focus on masculinity and femininity in terms of gender roles, so this limits the conceptualisation of gender to predetermined elements. They summarise their results by arguing gender and qualitative health research are a good match, because gender is a variable which cannot be isolated, and as such is a process. It is these processes within conceptualisations of masculinity and femininity that are of importance in terms of exploring how gender and health intersect.

It is clear that across the world, breast cancer has been established as a disease which affects mainly women, and one which is embodied through the pink, heteronormative, western assumptions of femininity. The position men are seen as being able to occupy within this breast cancer community is a supportive one. Men who have been diagnosed with breast cancer will, however, find themselves in a different situation from the men who are there as supporters. Men who are ill themselves are participating in this feminine

environment in a different way and will not be able to simply leave and return to their previous roles. By finding themselves in a female-dominated environment men with breast cancer have therefore become part of a minority group in terms of number. As a concept, hegemonic masculinity is useful as a tool for exploring gender relations within society. Hegemonic masculinity is seen in men who are physically fit, strong and dominant, and does not necessarily fit well with men who potentially are seriously ill. Previous research has overlooked the effects constructions of both masculinity and femininity may have on health and illness. Masculinity, and masculinities, are explored in this chapter, leading to a discussion of Connell's concept of hegemonic masculinity, and the criticisms which it has received. Breast cancer in men provides an ideal ground from which to explore the relationship between constructions of gender and how this can impact in multiple ways on health and illness. An overview of previous research into breast cancer in men is presented, and how there is a relevance for this research regarding how men experience being a breast cancer patient, and the mechanisms through which this is to be understood. An outline of hegemonic femininity is presented, linking into how breast cancer has evolved into the health social movement it is regarded as today. The intersection between these conceptualisations of hegemonic masculinity and hegemonic femininity positions men with breast cancer, and how their experiences are to be viewed.

Gender, illness and health

A definition of gender is first needed before the concept can be explored to show its relationship with health. Gender can be defined as a set of social practices which portray males and females as being different, and organises relationships between them on the basis of these presumed differences (Ridgeway, 2011). We live in a world which is structured around the idea that men and women have different bodies and therefore different abilities, needs and desires (Holmes, 2007) and sociologists have generally tried to view differences between women and men as socially constructed rather than natural. Gender is a tool for organizing social relationships, when defined as opposites one gender cannot be seen as existing without acknowledging the existence of the other (Lindemann, 1997).

People generally have a strong commitment to gender being a dominant way in which they understand themselves and others; this commitment helps reinforce gender stereotypes and gender also arguably acts as a base for inequality between individuals (Ridgeway, 2011). If men and women were homogenous groups then there would not be a need for terms such as masculine and feminine. The terms 'masculine' and 'feminine' move beyond the basic sex differences to the way that men differ among men and women differ among women (Connell, 1995). There is thus 'the ironic conclusion that gender is socially constructed yet is rigidly defined by sex category' (Dozier, 2005: 299) as it can often be difficult to consider one without considering the other.

The social constructionist viewpoint sees gender as being a dynamic social structure (Courtenay, 2000) and gender acts alongside other identities whilst shaping how the individual behaves in social situations (Ridgeway, 2011). Because it is presumed that stereotypes surrounding gender are shared broadly, this means individuals are able to use gender as a framework for their behaviour towards and with others. People do not have 'a free rein' when it comes to gender, they are having to act within conditions not necessarily of their own making; this may mean that sometimes other people may enact an individual's gender for them, in ways which may not be pleasing to that person (Holmes, 2007).

One of the seminal works within gender research has been West and Zimmerman's (1987) article 'Doing Gender', the purpose of which was to suggest a sociological understanding of gender which viewed it as an accomplishment both routine and methodological. The authors reported that in the 1970s gender was generally viewed as a status which was achieved, and constructed through a variety of means, psychological and social. It is individuals who do gender, but this doing has a situation – gender does not belong to the individual, it emerges from social situations. In Western societies, the accepted cultural view is that women and men are naturally defined categories. This means participants within an interaction organise behaviour and activities in order to display their gender, and also to react and respond appropriately to the behaviour of others, as individuals are used to seeing others as gendered. Gender can be defined in this approach as an

aspect of social interaction which is on-going (Deutsch, 2007) and therefore the approach of doing gender means creating differences between men and women which are artificial, and not essential (West and Zimmerman, 1987). Deutsch (2007) argues that the doing gender approach has benefitted research into the area of gender but such an approach may run the risk of undermining attempts to redress gender inequality by perhaps supporting the idea that the gender system is unlikely to be changed, and ignoring potential links between social interaction and structural changes. There needs to be a focus also on social processes.

The doing gender approach, in conclusion, 'has become a theory of conformity and gender conventionality, albeit of multiple forms of conventionality' (Deutsch, 2007: 108) and therefore if gender is constructed, it can also be deconstructed. There is the possibility inherent in this approach that institutions perceived as gendered can be changed and that social interactions which support such gendered institutions can be undone and changed as well.

An alternative viewpoint to the 'doing' of gender is the viewpoint of gender as institutional. Martin (2004) firmly argues gender is a social institution, and that by framing gender as such then this will lead to critical analysis and carry more potential for gender to be changed. Features of institutions include, but are not limited to, being a formal organisation as well as being viewed as fixed, consistent and unchanging. This latter element, however, is changing, so gradually there is a greater focus on conflicts and power, privilege and (dis)advantage.

Berger and Luckmann (1966) argued that institutions have a history: Martin refers to the work of Giddens (1984) by suggesting that institutions have recursive elements, as over time members of the specific group constitute and then reconstitute social institutions. In turn, institutions can be internalised by the people who constitute them. This can specifically relate to gender – as a social institution, it has a strong history in terms of how it has evolved over time, and how it is culturally-dependent. With more people learning and understand the norms and values of their particularly society, they in turn are able to constitute, and reconstitute, such social institutions.

Martin argues that social institutions have a number of features, including being collections of people who interact with one another and develop meanings; having specific social practices which recur; constraining as well as enabling behaviour; having particular rules and expectations and procedures; are internalised by members as identities; and are organised by those in power. By conceptualising gender as a social institution, this makes the origins of gender clear and also shows how it is perpetuated. It is not to be seen as 'natural' or an element of biology; rather it is 'the product of active human agents' (Martin, 2004: 1262).

A criticism of the model of institutional role theories is that it is too static and deterministic (Ritzer and Goodman, 2004). Rather than have a focus on institutions from a more macro vantage point, this should instead move to emphasising people's work in reproducing gender in interactional behaviours and practices, i.e. the 'doing gender' approach discussed previously.

As well as exploring the 'doing gender' approach, organisational structures need to be examined as they themselves are not gender neutral. As Acker (1990) argues, the gendered nature of organisational structure is in part hidden through how the nature of work is embodied. As such, there is a need to have a systematic theory of gender and organisations, as the gender segregation of work is created in part through organisational practices. Similarly, income inequality between genders is also partly created in organisational processes: it is imperative that these are understood in depth in order to understand gender inequality overall.

Organisations are an arena in which cultural ideas of gender are both invented and reproduced, they are not gender neutral despite discourses tending to conceptualise them as such. Citing the work of Smith (1988), traditional approaches to organisations originate in a male domain and therefore, Acker argues, reality is seen from that standpoint and gender as a whole is hard to see if only the masculine is present. Men in organisations take their behaviour as representing the organisational processes which are seen as gender neutral and it can be argued that gendered assumptions and attitudes are able to contaminate gender-neutral structures. Sexuality is also ignored, with behaviours such as sexual harassment seen as 'deviations of

gendered actors' not as part of an organisational structure (Acker, 1990: 143). Continuing with this line of discussion, Acker refers to the work of Moss Kanter (1977) who argued gender differences in organisational behaviour are not due to the characteristics of men and women as individuals, but rather to the structure of organisations. The problems women may encounter in organisations are due to their place structurally – in dead-end jobs at the bottom end of the hierarchy or seen as tokens in jobs at the top.

Giving consideration to the work of Acker is important as it shows there is a need to consider organisations in a different light – they are not static and separate from society, they can play a key part within it. Despite being viewed as gender-neutral, they reflect cultural ideas about gender and also reproduce these ideas and ideals. It is the fact they are seen as gender-neutral which has the potential to cause damage and have negative consequences. As such, when thinking about breast cancer and organisations, there needs to be a consideration of individual actors as well as wider organisational structures, in terms of how they are able to produce and reproduce gendered ideas and values.

Masculinity, and masculinities

Closely related to gender are the concepts of femininity and masculinity, which are hard to define: this may be because gender itself is changing and evolving and is 'politically fraught' (Connell, 1995: 3). As 'masculinity' is problematic in its description, it may be more appropriate (although no less straightforward) to use 'masculinities' as a concept, as it allows for a variety of ways in which men can enact their maleness. A multidimensional approach to masculinity allows for there to be individual and group experiences across a longitudinal time scale (Cameron and Bernardes, 1998). Throughout the lifecourse, individuals experience a range of contexts, situations, and environments which can impact upon their interactions and behaviour, and as such influence how they portray ideals such as masculinity, or femininity. The way a man at 19 behaves in order to be perceived as male may differ considerably from how he will behave at 39, and yet he still may be perceived as male by others due to the changing

ideals towards masculinity as he has grown older. It is doubtful that any one group within society is homogenous, and so to accept variability within a concept allows for it to be used in a multitude of ways, whilst not detracting from key ideals. Masculinity can be used as a starting point from which ideas about health, and men's attitudes towards it, can be drawn.

Recent years have shown an increased interest in issues regarding men and masculinities, with one definition of masculinity being a tangible thing, or a process which is continuing (Edley and Wetherell, 1995). There is a growing consensus that masculinities are constructed through discourse, although whilst individuals may be able to experiment with new and different versions of masculinity, there is no guarantee that these will be accepted as current ways of displaying masculinity. As such, men may prefer to rely upon constructions which are seen as being more entrenched and ones which have worked in previous situations (Edley, 2001). To an extent, it is the cultural history which influences the kind of identities men can assume. As such, whilst masculinity is seen as a performance, it is not necessarily a performance which is of the individual's choosing, and so the performances may be ones which are routine and habitual. In line with this, a masculine identity can be threatened if a man cannot perform in a certain way, and if he cannot display control over his body (Holmes, 2007).

A normative definition is what something ought to be, for example masculinity is what men should be, but in reality, a large number of men will not attain this normative definition. There needs to be acknowledgement that there are plural masculinities, but in a way which does not simplify them, for example black masculinity and white masculinity in the singular. There is also the need to explore relationships between the plurality of masculinities within society (Connell, 1995). In the late twentieth century, Seidler (1997) argued that this time period saw crises of masculinity take different forms for men of different generations, and that there was no one fixed ideal of masculinity to which each particular generation was aspiring to be. Whilst traditional ideas surrounding masculinity and masculine roles have been challenged, these are rarely replaced with an alternative. Sex role theories argue there are role concepts, and that for a man or a woman, in order for the individual to be seen as one, they have to portray a role which is definitive of that sex, and 'it allows a

shift away from biological assumptions about sex differences, emphasizing that women's and men's behaviours are different because they respond to different social expectations' (Connell, 1978: 48).

'All societies have cultural accounts of gender, but not all have the concept 'masculinity', which can only exist if there is a concept of femininity (Connell, 1995: 67). A positivist definition would be what men are, focusing on fact, but there can be no description without there being a basis, and it is debatable whether this basis can be neutral (Connell, 1995). 'Mass culture generally assumes there is a fixed true masculinity beneath the ebb and flow of daily life' (Connell, 1995: 45) and so true masculinity comes from the male body, for example the body has direct action, such as an urge to be violent. However, linking this to essentialist definitions, in such a definition a particular feature is seen as the core of masculinity, and the focus is on that. There is the risk here that this is over-simplified and perhaps an arbitrary choice of core feature. What also needs consideration is that there are inequalities for both men and women, so 'the politics of masculinity cannot concern only questions of personal life and identity. It must also concern questions of social justice' (Connell, 1995: 82-3).

Hegemonic masculinity

Schippers (2007) argues that the essence of gender difference establishes the relationship between femininity and masculinity. However, difference and complementarity do not equal hegemony. The hegemonic features of a culture serve the interests of the ruling group and legitimates their dominance. Sexual relations define masculine sexuality in relation to femininity, as heterosexual sex is still reduced in Western constructions to penetrating and being penetrated.

Hegemony can be defined as 'the cultural dynamic by which a group claims and sustains a leading position in social life' (Connell, 1995: 77) and involves the majority of the population being persuaded that the way a particular social institution is organised is natural and normal (Donaldson, 1993). A supporting definition of hegemonic masculinity is 'the power of certain groups of men to force an interpretation of what masculinity should

be and, thus, to subordinate or repress other styles of masculine expression and women more generally' (Edley and Wetherell, 1995: 129). One form of masculinity is generally viewed as being above others but this can change, and whilst there may be alternative forms of masculine identities, these are still usually seen as subordinate to the hegemonic identity (McVitie and Willock, 2006). Developing in the mid-1980s, '[H]egemonic masculinity was understood as the pattern of practice (i.e. things done, not just a set of role expectations or an identity) that allowed men's dominance over women to continue' (Connell and Messerschmidt, 2005: 832). Hegemonic masculinity is constructed in relation to women as well as subordinated masculinities (Connell, 1987). It is interesting to consider that there is not perceived to be a hegemonic femininity in the way that there is a hegemonic masculinity.

Realistically, not many 'men actually behave according to the hegemonic masculine pattern, although it is a standard to which all men are compared' (Holmes, 2007: 57). However, it is normative and embodies what is currently the best regarded way of enacting masculinity, whilst requiring all men who do not embody this masculinity to in some way place themselves in relation to it. Hegemonic masculinity can include physical strength and such characteristics legitimate men's dominance over women when they are paired with an inferior quality associated with femininity, such as physical vulnerability. Even if not many men and women embody these characteristics, the symbolic relationship is established (Schippers, 2007).

By definition, hegemonic masculinity as a concept presumes that there is a subordination of masculinities which are deemed to be non-hegemonic, and possibly the concept as a whole needs reformulating, to reflect the need to have 'a more holistic understanding of gender hierarchy, recognizing the agency of subordinated groups as much as the power of dominant groups and the mutual conditioning of gender dynamics and other social dynamics' (Connell and Messerschmidt, 2005: 847). Emphasis also has to be given to considering the context of place.

As what is deemed to be the current hegemonic masculinity is generally well-known, men are able to adopt hegemonic masculinity strategies when it is desirable to do so, but equally the same individuals can also distance

themselves from these ideals if that is the more appropriate course of action. Consequently, “‘masculinity’ represents not a certain type of man but, rather, a way that men position themselves through discursive practices’ (Connell and Messerschmidt, 2005: 841). One area of social life in which this can be seen to be occurring is health, right from the acknowledgement of symptoms, through to engagement with medical professionals and institutions, and the incorporation of an illness identity into everyday life (for example, Oliffe, 2009). As has already been argued, gender is a key element to a person’s identity, in terms of how they see themselves, as well as how others see them, and as such how gender is linked with health care, illness, and illness prevention is fundamental to exploring the overall relationship between illness and identity.

Schippers (2007) had the goal of placing the feminine other at the centre of theories on gender hegemony. The use of the term ‘other’ reflects how femininity/feminine have been defined in work on masculinity. Based on Connell’s (1995) work, masculinity can be seen to have three components, namely a social location that people can move into through practice, regardless of their gender; a set of characteristics and practices which are understood as being masculine, and when these practices become embodied by both men and women, they have social and cultural effects which can be widespread. Occupying a masculine position affects the ways people experience their bodies and their self, and also how this self is projected to others.

It is important that hegemonic masculinity is understood as a social process, as this shows how ideas surrounding masculinity can change over time as well as be context-specific. As Connell and Messerschmidt argue, ‘[T]he concept of hegemonic masculinity presumes the subordination of nonhegemonic masculinities, and this is a process that has now been documented in many settings, internationally’ (2005: 846).

Hegemony ascends via cultural and social institutions as well as through persuasion. Hegemonic masculinities can be constructed in ways which do not closely correspond to the experiences of individual men, as they are models, but the models do reflect widespread desires and ideals (Connell and Messerschmidt, 2005). These models provide further guidance as to

how men are supposed to relate to women and other men, following ideals as to how to live as a man in everyday life. Masculinity is not one type of man, it is a way in which men position themselves through discursive practices. The hierarchy of masculinities is a pattern within hegemony, and it is not dominated based on force. Considering hegemonic masculinity as a social process, this means that whatever the dominant pattern of masculinity in a society can be changed and challenged. The conditions in which masculinities were formed change over time and therefore hegemonic masculinity can be constructed and reconstructed.

P. 846: -‘Cultural consent, discursive centrality, institutionalization, and the marginalization or delegitimation of alternatives are widely documented features of socially dominant masculinities.’

Connell (2005) emphasises the necessity of there being interplay between different types of masculinity, in which masculinities are negotiated in relation to a reference group, in this case being the ideal of hegemonic masculinity. As Wedgwood (2009) argues, these types of masculinity are important as they show how hegemonic masculinity manifests itself through patriarchal structures, as well as highlighting how masculinities are socially controlled and also how hegemonic masculinity is able to transcend the wider social structures in which masculinities can be seen as context-specific.

The four types of masculinity account for different masculinities through its complexity, and also show the relationship between privilege and power. Complicit masculinity refers to men who do not display enact a strong ideal of masculine dominance, yet they still received the benefits of patriarchy and so are seen as displaying a complicit masculinity. With heterosexual women being compliant, this is the group in which the concept of hegemony is most powerful. If hegemony is effective then there is likely to be an amount of blurring or overlap between hegemonic and complicit masculinities (Connell and Messerschmidt, 2005). Subordinated masculinities are masculinities which are less legitimised, such as gay men. Individuals who embody a subordinated masculinity are likely to experience political and cultural exclusion, as well as be more vulnerable to violence and economic discrimination (Connell, 2005). Marginalisation stands for

challenging particular masculinities and their claim to legitimacy, and it is here there is an interplay between dominant and subordinated masculinities. As Connell (2005) argues, those who reject hegemonic masculinity have to find another route, one in which the specific marginalisation in the norm.

Marginalised ethnic groups, for example, can be seen as embodying protest masculinities: Connell and Messerschmidt (2005) refer to the work of Poynting, Nobel and Tabor (2003) who argued protest masculinity can be understood as a pattern of masculinity contrasted in a working-class setting, sometimes among men who are ethnically marginalised. There is the claim to power which is typical of hegemonic masculinity in Western countries, but this protest masculinity lacks the institutional authority and economic resources that underpin the patterns of hegemonic masculinity globally.

Hegemony can also be seen in terms of external hegemony, men's dominance over women, and internal hegemony, the dominance of one group of men over other men (Demetriou, 2001). This again reinforces the understanding of hegemonic masculinity as a social process: as groups change and fluctuate, and as individuals move amongst and between their social groups, relationships between hegemonic and non-hegemonic groups are being negotiated in ways which allow for the hegemonic ideals to retain their dominance.

The aim of Schippers' (2007) paper was to rework Connell's theory of gender hegemony and masculinities in a way which does not reduce femininity to the behaviour of girls and women and masculinity to the behaviour of boys and men; it also provides a definition of femininity that allows for there to be multiple configurations, and to be useful empirically for identifying how femininity and masculinity ensure the domination of men over women. There is a need to place femininity back into the theory but without losing the conceptualisation of hegemonic masculinity. The categories 'man' and 'woman' have symbolic meanings, and these meanings establish the origin, significance, and quality characteristics of each category. For example, origin could be biology or socialisation, significance the foundation of society, and characteristics could include men being seen as strong, and women as compliant.

The focus of Shippers' (2007) argument here is on quality content. There are qualities that members of each category are expected to possess, and Schippers argues in contrast to Connell and Messerschmidt (2005) that the hegemonic significance of masculinity and femininity is found in the idealised quality content of the categories 'woman' and 'man'.

Critiques of Connell's hegemonic masculinity

Whilst Connell's ideas surrounding hegemonic masculinity have been widely used within academic literature, they have not been accepted entirely without reservations. Even though it may be an established view, there are areas in which the concept of hegemonic masculinity may be seen as problematic.

Martin (1998) raises questions concerning Connell's *Masculinities* and the definition of masculinity being a place in gender relations. In this place, men and women engage with one another through practices, and there are effects which these practices have in terms of bodily experiences, culture, and personality. Overall, it is an on-going process rather than being one which is stable. Martin accepts masculinity is a practice, and as such 'man' and 'woman' are places in a system of gender relations, but finds it harder to view how masculinity is a place or an effect. For example, if a man dresses as a woman, then is he in a feminine or masculine place? There is an argument presented here that one needs to understand the gender norms of that society in order to understand whether a particular behaviour is to be perceived as masculine or feminine.

Connell argues that hegemonic masculinity is not a *type* of masculinity, but is the type that is dominant at a given time, however many scholars do use it as a type, and it is usually seen as negative (such as violence, dominating) (Martin, 1998). Martin posits that Connell is sometimes inconsistent, representing hegemonic masculinity as a 'type' (e.g. contrasting hegemonic masculinity with homosexual masculinity) and then later noting that competitive masculinity is the kind that is hegemonic in institutions today, thus using the 'whatever is dominant' form. As such, the utility of the concept is weakened when authors use it as a type because this means they do not have to explain what the hegemonic type is at the time of the study.

Conflation also means Connell's claim that the types that are hegemonic are always being contested, is undermined, and also undermines the claim that hegemonic masculinity can be positive. This claim that hegemonic masculinity can be positive may well be appropriate for a number of situations and contexts, but cannot always be said to be true, especially on a broader scale. By definition, hegemonic masculinity is the dominant form of masculinity in a particular time and place: whilst this may be beneficial to some individuals who assume the associated definitions, it may be detrimental to others who do not conform.

A second reservation surrounding the concept of hegemonic masculinity is how the concept itself, as well as the hegemonic relationship between masculinity and femininity, can be threatened by women who may practice features of hegemonic masculinity, such as being sexually attracted to women, or having multiple sexual partners. In such a situation, they are women who are utilising features of hegemonic masculinity in a way which could threaten the overall dominance of hegemonic masculinity. Schippers (2007) suggests these women are called 'pariah femininities'. They are not subordinate, as they are not necessarily seen as inferior, and instead are seen to contaminate the relationship between femininity and masculinity. Even though these women are not viewed as men, they are also not viewed in the traditional sense of being women, and as such are in a position to weaken the relationship between hegemonic masculinity and its subordinate femininity. Possessing one of these aforementioned qualities is assumed to contaminate the individual, is socially undesirable, and contaminates social life in a more general way, by being in a position from which to disturb the current equilibrium. Whilst pariah femininities may contain hegemonic masculinity qualities they are definitely not masculine, they are still seen as feminine, but not an ideal form of feminine. An authoritative woman may be seen as cruel and undesirable, but nonetheless still feminine. A woman who has multiple partners is seen as very feminine and a lesbian is often seen as an object of desire by men.

In contrast, continues Schippers (2007) pariah masculinities do not exist as such in the same way. For example, gay men are seen as feminine, due to their sexual attraction to men, and because femininity is already inferior when compared to masculinity, it is able to sustain elements of

stigmatisation. Contrasted with this, masculinity must always be superior, and never associated with something undesirable. As such, no masculine characteristics are seen as subordinate or contaminating. Hegemonic masculinity as a concept in this situation is almost seen to be omitting other types of masculinity, and perceiving them as feminine, rather than as a form of masculinity which is just subordinate to the type which is currently hegemonic. Rather than just viewing another type as inferior, it is potentially removing it entirely and viewing it in another way, as in this scenario homosexual masculinity is removed almost entirely from the realms of masculinity and potentially interpreted as a form of femininity, based solely on the sexual attraction these men have to other men. Hegemonic masculinity as a concept might be interpreted as being the only form of masculinity, if other types of masculinity run the risk of just being relegated, almost, to an inferior level with types of femininity.

There is also the argument that men need to be treated as a gender as well as women, and as such masculinity needs to be examined too. Lorber (1998) comments that men's feminism has been successful in terms of analysing the social construction of masculinities from a man's point of view: however, it misses the depth of resentment and anger that women's perspectives have to the potential to bring to the analysis. This is similar to white feminists discussing racism, and feminists of other ethnic origins discussing the same matter, and the different perspectives they would have on the matter in question. There is the need to experience certain things and whilst it is possible that feminists do appear to feel the unfairness of men's domination over men, they do not seem to feel the same resentment that women may feel about being dominated by men. Arguably, it needs to be men who do not fit in current definitions of hegemonic masculinity who are best placed to critique the concept as a whole, as their position may give them insights and depth that is currently unavailable to others.

Continuing with this idea of gender, Connell (1998) replies to Martin and Lorber and acknowledges the complicated definition of masculinity arose due to a strong sense of the multidimensional character of gender, and how no 'core' idea of masculinity is sufficient. In answer to Martin's question explored earlier as to whether masculinity can be a place or an effect, Connell replies that in relation to place, when a man is in drag he is

occupying a feminine place in terms of ideas of dress, but he does not need to be feminine in other structures at the same time e.g. in terms of the division of labour. With regards to effect, practices such as clothing and work have bodily effects and can be seen as part of the construction of gender. Connell argues that the interaction between social processes and bodily processes is of importance and as such should be included in definitions of masculinity and femininity. Connell concluded by arguing that hegemonic masculinity is defined in relation to how patriarchy is legitimated. It may be seen as negative but can be positive. It is possible that a hegemonic ideal could be constructed for masculinities which is less toxic than what is current now.

As has been demonstrated above, the concept of hegemonic masculinity is useful as a tool for exploring gender relations within society, and as a starting point for an analysis of how ideas of hegemonic masculinity may impact on other areas of social life. However, the established view can be seen as problematic, and it runs the risk of becoming normalised, if it is not already viewed as such. It could be argued that a situation is viewed as natural, because it has been normalised, but this does not mean that it is entirely a natural phenomenon. Relating this to breast cancer, it is seen as natural that women get diagnosed with breast cancer, because they have natural breasts. This, however, pushes to one side the facts that not every woman will one day receive a breast cancer diagnosis, despite them having breasts, and that men can get breast cancer too. In line with this, the cultural and moral orders surrounding breast cancer, breast cancer awareness campaigns and communities are not natural, they have evolved over time. They have been constructed and built over time, through the social interactions of individuals and groups, using cultural norms and values as foundations. It is these cultural ideas which need to be considered alongside current ideas surrounding hegemonic masculinity, as they cannot be considered in isolation from one another.

Research on breast cancer in men

So far, this chapter has demonstrated how breast cancer is viewed as a female illness, and how in order to understand what is meant by a 'female illness' there is a need to understand the relationship between gender and

health. Conceptualisations of gender have been outlined, focusing on the argument that it is socially constructed in nature, and needs to be considered alongside other social contexts. Ideas surrounding masculinity and hegemonic masculinity have also been addressed, and how such attributes and behaviours may be influential or detrimental when it comes to health and engagement with the medical profession. Connell's concept of hegemonic masculinity has shown that whilst a form of masculinity can be seen as dominant, this is not necessarily natural and there are cultural ideals around this. Breast cancer is seen naturally as a women's disease as women have breasts. Focusing on the relationship between identity and illness, cancer is by its nature a lengthy illness which will require a high level of engagement with medical professionals and as such offers a key vantage point for examining the relationship between illness and identity. The in-depth focus on men diagnosed with breast cancer allows for a deeper analysis and further investigation, as it is approaching the illness from a different viewpoint, one which is often in stark contrast to the viewpoint witnessed and experienced by women diagnosed with breast cancer. It is this approach which can reflect the cultural assumptions surrounding breast cancer and how a critical understanding of hegemonic masculinity is needed in order to understand the experiences of men diagnosed with breast cancer.

As a starting point, men receiving a breast cancer diagnosis share aspects similar with women receiving a breast cancer diagnosis. Breast cancer is viewed as a "women's disease", one about which there is a plethora of information available for women, yet very little specifically for men. Public awareness and knowledge of breast cancer in women is high, but there is a lack of such information when it comes to the disease in men. As such, breast cancer in men can be seen as suitable illness for investigating further men's health, their attitudes, and how this meets with conceptualisations of masculinity, as its rarity contrasts with the dominance of breast cancer in the minds of women. As Donovan and Flynn posit, 'little is known about the ways in which men accommodate an illness that connotes such clear associations with femininity and these issues are not evident in other disease profiles' (2007: 464-5). Breast cancer in women is one of the most widely studied illnesses, and by moving the focus on to men, the contrast is provided, as an understanding of the minority group can help with an understanding of the majority group. Due to the relatively small number of

men diagnosed each year, little biomedical research is conducted into breast cancer in men due to the lower number of individuals likely to be able to participate. Therefore the research explored here is from a more sociological perspective.

‘Male breast cancer constitutes a unique lived experience for men that is unparalleled in other disease profiles’ (Donovan and Flynn, 2007: 464) yet predominantly due to the relatively few number of men diagnosed each year with breast cancer, there is little research involving male patients in comparison with research involving female breast cancer patients. In their qualitative study of male breast cancer patients, France et al (2000) found, through anecdotal evidence, male breasts are considered only anatomically, with little sexual or emotive association and that little attention is given to body image in men. The aim of their research was to describe social and psychological consequences of the diagnosis of breast cancer in men. The researchers argued that results could have implications for clinical management, as well as service provision; many men in the study reported delaying in going to the doctor initially, and two patients had to persist with being seen. This potentially is due to perceived embarrassment about being seen as worrying about a ‘women’s disease’. Considering coping strategies for altered body image, participants tended not to discuss their diagnosis with colleagues, and none of the men in the study has been offered any information specifically regarding breast cancer in men, although some had been given information for women with breast cancer. As mentioned above, whilst research has shown that breast cancer in men and woman may be very similar, there are issues which are not the same (for example, breast reconstruction following surgery) for both sexes, and it seems inappropriate to provide seemingly useless information to patients.

The purpose of the study conducted by Brain et al (2006) was to investigate how prevalent psychological stress is in male breast cancer and ‘factors associated with increased distress’ (p. 95). 161 men responded to a cross-sectional questionnaire, addressing anxiety measure, body image, cancer-specific distress, information and support, and other variables such as clinical and demographic. Six per cent of men reported avoidance coping, uncertainty, and one per cent of men reported levels of depressive symptoms. 23 per cent had high levels of cancer-specific distress. A risk

factor for distress was identified as respondents felt that their needs for relevant information were not being met. The research also argued that there is a lack of public awareness and strategies currently based on those used for women, and this is something that may need addressing if parity is to be achieved. As shown above, research has shown that breast cancer in men and women is quite similar, and seeing as how the scope for clinical trials with men is small, due to the small number of men diagnosed each year, there may be an implication here that the information available to men is relevant, it just ought to be presented in a format which is more accessible and acceptable for male patients. As Brain et al argued gender specific information is an under-researched area. Studies have found that male patients of cancer generally have found high levels of distress, but there are higher scores in women. The factors involved with distress in men diagnosed with breast cancer need to be understood in order to identify the men who may benefit from more emotional support. There needs to be an increased knowledge as to how men may portray raised levels of distress, so that these can be addressed early.

An earlier study found that '[m]any men who are diagnosed with breast cancer do not discuss their disease with anyone outside of their immediate family. This tendency, combined with the rarity of the disorder, also contributes to many being unaware that men are capable of developing breast cancer' (Bunkley et al, 2000: 94). Consequently, when a man is diagnosed he may have feelings of confusion and disbelief, as well as isolation. He has become isolated from a majority group of healthy men, to find himself within a minority group of men with breast cancer, within a majority group of women diagnosed with the illness. Coming to terms with the diagnosis of a 'feminized illness' can be distressing for some men (Donovan and Flynn, 2007: 464) and consequently, men may be too embarrassed to attend a breast cancer support group, even if they are aware of the benefits women gain from attending such groups (Bunkley et al, 2000). As Williams argues, 'different conditions carry with them different symbolic connotations and imagery, which vary markedly within different segments of the cultural order' and will influence how the individual sees themselves, but also how they think they are seen by others (2000: 44). There is also the potential risk that joining a support group for women would further feminize the man, in terms of how he sees himself, and also in

terms of how he perceives himself to be seen by others. Whilst the breast for men does not have the same symbolic meaning or significance as the female breast, its removal or disfigurement will create scarring, and change the appearance of the chest area (Donovan and Flynn, 2007) so women are not alone in finding they have to come to terms with seeing themselves physically in a different way.

Men who are diagnosed with testicular or prostate cancers can claim ownership of their illness as they are forms of cancer which can only be found in men, and therefore can carry on portraying a masculine identity. However, side effects of treatment may include problems such as erectile dysfunction (Donovan and Flynn, 2007) and this could impinge on a sense of masculinity. As Sulik argues, '[t]he masculine ethos of survivorship aligns with traditional masculinity such that any man who takes on these characteristics can be manly and fight cancer at the same time' (2011: 84) meaning that key aspects of masculinity, such as strength, are needed in order to survive the illness, and perceptions of masculinity. By drawing on their ideas of what it means to be masculine, these could overcome problems produced by the illness diagnosis. In comparison, as 'femininity is socially devalued in the binary system, men who prefer the feminine ethos of survivorship risk demasculinization' (Sulik, 2011: 88-9) and so even when faced with a 'women's disease' men need to rely on strengths of masculinity in order for others to continue to perceive them as male. The dilemma of a man being diagnosed with a 'female' illness is phenomenologically symbolized as a battle in which masculinity needs to be defended against a feminized threat (Donovan and Flynn, 2007). In order to be perceived as masculine by others, men need to defend what it means to be masculine against the contradictions being aimed at them from the female threat of breast cancer. The vocabulary surrounding warrior language implies in a battle there can only be one winner, and masculinity and breast cancer are in competition to see which will dominate.

Men may have their masculinity threatened by a breast cancer diagnosis, but 'an understanding of how men address these challenges by adopting and adapting the masculine characteristics of stoicism, self-determination, and courage can facilitate and enhance the care of this group' (Donovan and Flynn, 2007: 469). In order to re-establish their legitimate masculinity

following this feminized threat, the participants in this study had to accommodate the changes the threat had made to their body and learn to live with altered images as to what the disease represented. If men are marginalised, 'albeit in a non-deliberate or malign way, health professionals [are] complicit in upholding the stigma' of breast cancer in men (Donovan and Flynn, 2007: 468). Information cannot just be transposed from women to men, as such information may run the risk of alienating men and further reinforcing the stigma of breast cancer in men.

Bringing the research up to date, Thomas (2010) argued that as the rate of cases of breast cancer in women is rising, this has implications for men as around 15-20 per cent of men diagnosed with breast cancer each year have a blood relative with a history of the disease. Breast cancer in men has not been given much attention by the general population or the health care community and '[n]ew public health initiatives are needed to educate the public and health care providers, to raise awareness and facilitate early detection' (2010: 32-3). Thomas conducted a literature review prior to his interviews and found that '[i]nformation on what the general public knows about male breast cancer was entirely lacking' (2010: 34) showing that this has not been an area researched before, which could be damaging to the health of men. In the interviews for his research, respondents were asked if they would question their masculinity if they were given a breast cancer diagnosis. Those interviewed by a male interviewer said they would not, whereas a few interviewed by a female interviewer said that they might. Men may be afraid of showing how they might question their masculinity, if put in such a position, to other men, who may view them as less of a man for doing so. However, this can be seen as less of a threat if admitted to a woman. Similarly, Thomas found that the interviews with men were generally shorter than expected, with men possibly being affected by what to say to researchers as they may have difficulties expressing their emotions, especially as a breast cancer diagnosis was for them, currently, a hypothetical situation.

The participants in Thomas' study each commented on how important it is for people to know that men can be diagnosed with breast cancer too, and how men with a family connection with breast cancer need educating about the real possibility they could be diagnosed. It is important for the health

care profession to understand that what is effective for educating women is not necessarily going to be effective for men, as it is 'not enough to simply change the word "female" to "male"' (Thomas, 2010: 39). Equally, Thomas also argues that many health care professionals do not yet believe that breast cancer in men is a problem worth researching, and this can impact upon the information readily available to patients. When respondents were asked how they would suggest educating men, recommendations included placing information in the media more prominently during October (breast cancer awareness month), and also leaving leaflets at sports events and other places men frequent such as bowling alleys and barbershops. Held within these suggestions is the implication that in order to educate men, information needs to be taken to them, rather than hoping that men will come to it. By placing educational materials in venues men visit socially, the effort has already been made for them, and health information is taken from something which is perhaps intimidating to something which can be found within a relaxed social setting. The suggestion from the respondents in this study to leaving leaflets in 'masculine' places such as at sports venues implies that these are areas frequented by men, with men, and that it is generally a place which does not have many women present: this masculine environment may help aid men in being receptive to learning about breast cancer, as they are around other men and do not need to feel as outsiders to the majority group of women, who are usually much more informed than they are. However, it can be argued that the presence of women, especially as wives, is important in enabling men to become involved with their health. In their study of screening for colorectal cancer, Thompson, Reeder, and Abel (2011) had one respondent suggest that men need to be targeted differently from women, perhaps through their wives, although this assumes that men are partnered with women and that these women would be willing to participate. This reliance on women also reinforces the perception that health concerns cannot be held alongside a masculine identity, and as such women are needed in order to ensure their male relatives are engaging to the extent necessary with their health.

Much of the research outlined here focuses on men diagnosed with breast cancer as individuals, for example the research by France et al (2000) on how men's breasts were viewed in an anatomical light, with little attention paid to body image. Brain et al (2006) demonstrated the growth of

psychological stress and distress in men with breast cancer, and Bunkley et al (2000) showed how men were unwilling to discuss their diagnosis outside of their circle of close family and friends. As explored earlier in this chapter, regarding masculinity as a social construction, rather than being a completely natural phenomenon, is relevant as it allows for individuals to experience a range of contexts and situation throughout the lifecourse which can impact upon their behaviour and therefore how they portray an ideal such as masculinity. Masculinities can be viewed as being constructed through discourse, and how one wishes to display masculinity may not be seen as such by others, meaning individuals may have to rely upon a construction which is more accepted. The performance, as such, is then not necessarily of the individual's choosing so performances may be routine, implying masculinity can be threatened if a man cannot act in a certain way. Hegemonic masculinity is not necessarily natural, and there are cultural ideals around this. Whilst research on men diagnosed with breast cancer has, to some extent, addressed these conceptualisations, the emphasis is very much on the individual, and how his experiences affected him. In order to explore how men experience being breast cancer patients, and how this is to be understood in terms of showing the mechanisms through which men are less able to participate in the breast cancer community, these concepts need to be utilised in terms of researching social interactions, social groups and social worlds, moving the focus beyond just the individual.

Hegemonic femininity

The previous section positioned breast cancer in relation to hegemonic masculinity, and how research into breast cancer in men has shown the feminized threat breast cancer is to men and their self-perception of masculinity. Gender is a dichotomy, with it being hard to consider one without the other. Therefore, in order to understand how men's experiences of breast cancer are to be understood in terms of hegemonic masculinity, it is necessary to consider whether in the same way there is a hegemonic femininity. Hegemonic masculinity is the subordination of femininity and the marginalisation of other masculinities, and Connell argues there is not a hegemonic femininity as all forms of femininity are contextualised within the subordination of women to men (Schippers, 2007). In terms of an emphasised femininity, women can enact hegemonic femininity by

complying with the subordination of women. However, there could be a definition of hegemonic femininity as consisting of the characteristics that are perceived as womanly, and these both establish and legitimate a relationship to hegemonic masculinity which is hierarchical. Therefore, this guarantees the dominant position of men, and the subordination of women. Harris and Clayton (2002) agree, in that the concept of hegemonic femininity serves the same purpose culturally as hegemonic masculinity, in which male hegemony is established, rather than hegemonic femininity implying the hegemony of women.

Hegemonic femininity is arguably best seen in terms of sports, and specifically how women in sport are perceived and treated. Figure skating is seen as feminine, and ice hockey seen as masculine, and individuals who cross these boundaries are viewed as anomalies. Sport is defined by traditional standards of masculinity so these conflict with hegemonic femininity. Being too muscular is seen as unfeminine, too masculine, and socially unacceptable, with the added possibility of female athletes being assumed to be gay because they are not conforming to ideas of hegemonic femininity (Krane, 2001).

Harris and Clayton (2002) researched how hegemonic masculinity and hegemonic femininity are constructed and maintained within sport, focusing on the female tennis player Anna Kournikova, and how sport was reported in two British tabloid newspapers. There is a suggestion that female athletes are underrepresented in an attempt to keep sport seen as a male area. At the time of their research, Kournikova was one of the most well-paid female tennis players but had yet to win a major tournament. Kournikova embodied almost exactly the hegemonic femininity ideals of female physicality and behaviour, except perhaps that she is an athlete. The visibility of Kournikova may not help a move towards equality in sport and instead may just hold the current gender order, because in so many ways she epitomises hegemonic femininity. The focus on Kournikova also reflects how appearance is more important than nationality in women's sport. The sports world implies that sexuality is more important than ability. Hegemonic femininity is clearly shown here as female athletes who are seen as lacking the attributes the tabloids exploit receive a proportion of coverage which is unequal. Newspapers in this sense appear to have a dual approach,

to promote ideals of masculinity and superiority in men whilst also (mis)representing women athletes as maintaining attributes of sensuality, heterosexuality, fragility and subordination. Krane (2001) argues that there is a careful balance in women's sport with regards to how they are perceived, as those who are seen as feminine are privileged over women perceived as masculine in sports, but if they are seen as too feminine, then they are trivialised. Within this is a message that femininity and sport are contradictory, and women have to emphasise how they can be athletic as well as socially accepted.

Hegemonic femininity is seen as emotional, dependent and passive, gentle and maternal, and sportswomen who follow the defined acceptability for hegemonic feminine appearance are rewarded with sponsorship and fan attention, whilst women who do not may not be as successful, with negative treatment by the media. The success of athletes who are also models leads others to believe they also need to look like a model in order to be successful (Krane, 2001).

The conceptualisation is relevant for researching men diagnosed with breast cancer, as hegemonic femininity links directly with commonly held assumptions about the illness and those diagnosed with it. Hegemonic femininity is associated with particular ways to act, dress and behave, and many of these have a focus on breasts and sexuality. Hegemonic femininity does not mean directly the hegemony of women, but rather it establishes and legitimates a relationship to hegemonic masculinity which is hierarchical. In terms of researching breast cancer, the introduction to this thesis demonstrated how breast cancer is positioned as being a disease of, and for, women and is strongly associated with characteristics linked with the current conceptualisation of hegemonic femininity, and yet this is a community which, for once, is dominant over men and threatens their conceptualisation of their own hegemonic masculinity.

Breast cancer as a health social movement

Having considered what is to be understood by hegemonic masculinity and femininity, these can provide a base from which individuals may find themselves positioned when entering the breast cancer community. In order

to explore how men experience being a breast cancer patient, there needs first to be an understanding of breast cancer as a health social movement. According to Epstein (2008) the health social movement around breast cancer is the one which has been most extensively researched from a science and technology studies perspective. There are a number of reasons as to why breast cancer has become so visible. Zones (2000) argues that it covers population subgroups as well as different political areas, and in doing so is able to create interest groups with quite a broad base. Equally, the high number of breast cancer patients may mean that people have been affected by breast cancer, either directly or indirectly, more so than they have been by other diseases and health conditions. There is also the element of gender. In Gibbon's (2008) research into a breast cancer charity, about 90 per cent of the supporters were female, and more than 50 per cent were aged under 45 (lower than the median age of diagnosis). Gibbon argues that it is this ethos which has been so important in terms of raising awareness of the disease and generating support for research. A study conducted by the charity in this study found that two thirds of fundraisers had not had breast cancer themselves, and many identify with the organisation as a way of remembering relatives. Illness experiences are shaped by individual circumstances as well as cultural and spatial practice regimes; the 1990s saw a growth in breast cancer organisations, as the 'public identity of women with breast cancer was transformed from tragic victim to heroic survivor' (Klawiter, 2005: 163). It is this framing of breast cancer patients that is crucial to developing an understanding of involvement with social movements and how frames allow for people to produce meanings.

In a more historical account of breast cancer movements, in the 1970s breast cancer patients were seen as revolting against standard medical practice. In the 1990s, the breast cancer movement was dominated by predominantly middle- to upper-class white women (Lerner, 2001): whilst African American women do have a lower rate of breast cancer, they tend to go for medical help at a more advanced stage. There is the potential here for a different strand of breast cancer movement to develop, one which has the possibility of meeting the needs of a different population group of women, who have a different identity and a different interpretation of their illness. Showing similarity with the development of other health social movements and patient advocacy organisations, the breast cancer movement too

emerged from a background of white, educated, middle class women, and from the perspective of health provision in the United States, insured. This particular demographic of women was not, and arguably is not today, the most marginalised cancer patient group, but the one which was most medicalised, meaning this group had ownership of, or access to, the resources required to create and begin a social movement (Klawiter, 2008). This demographic of women had access to leading medical treatment, and would have been aware of to what they were entitled and how this could be obtained. As such, this shows that patient and social movements do not need to originate with people who are marginalised; whilst marginalised people may feel that the mainstream culture does not fully meet their needs, they may not have the social capital required to develop and launch a relevant social movement.

Breast cancer activism, like AIDS activism in the 1990s, is often viewed as being an excellent example of how mobilization has helped to raised awareness of the disease, promote the rights of women, and examine gender inequalities within scientific research and the provision of healthcare (Frickel et al, 2010). Breast cancer activism involved many culturally diverse groups and as such the issue of undone science is different across national and international groups. Environmental risk factors are often marginalised in discourse. Gibbons (1997) argued that very few women involved in a leading breast cancer charity saw their involvement in terms of developing a research agenda, or influencing the research aims of the charity. Their narratives did not refer to influencing research, as they felt that should be left to the scientists. Overall, the interview data suggested that breast cancer has growing activism and a more open relationship with developing advocacy, but there is still an institutional context which sustains and influences mobilization associated with the disease.

The existence of online forums about breast cancer show how sharing the same disease diagnosis can create bonding and solidarity between users. Landzelius (2006) found that there was some talk which was politicised in nature on forums for people diagnosed with breast cancer, but very little which was specifically aimed at developing agendas to tackle certain political issues. This may show that very gradually, different types of activism are on the rise, especially ones which focus on health issues.

Scholars are trying to move their analysis beyond that of the patient group on its own, in order to examine the cultural and institutional webs in which they are entangled. As the internet has become more significant for the development of patient groups, there has been an increase in analysing data found online (Epstein, 2008). What is also important to note here is that advocacy groups are not necessarily organised by patients, they may be organised by parents, or carers, or advocates, and as such the contexts of the people diagnosed with the health condition may be broader than perhaps initially conceived.

In her research into breast cancer activism and politics in America, Klawiter (2008) reflects upon the theory of political process, in which social movements have as their target the nation-state, and need to create and take advantage of political opportunities in order to develop and be successful. However, this idea is possibly no longer as popular as it once was, as the causal importance of factors such as perceptions and ideas is underestimated. This can, though, be viewed as a simplistic conceptualisation and one needs to consider new developments such as the growth of science and medicine. An alternative theory is that of new social movements theory, in which collective identities and the social movements they developed were produced structurally as well as being constructed socially (Klawiter, 2008). The last decades of the twentieth century saw the development of patient groups for almost all health conditions, often aiming to challenge governmental priorities and practices of scientific research and medicine, as well as challenging pharmaceutical companies. All of this has the consequence of blurring the boundaries between the state, medicine and science, corporate philanthropy, and social movements. By becoming more active in their role as individuals diagnosed with a certain medical condition, people have been able to link with others in a similar situation and as such challenge accepted ideas about, for example, treatments and drug regimens. Medicine can still be regarded with high esteem, but an arena is developed in which patients become experts in their condition: this knowledge can be used to challenge ideas about how best these individuals can incorporate their identity as a person with this medical condition. Similarly, individuals may be able to join with other people to research and share ideas and experiences as to what has worked for them and may work for others. Such shared knowledge could lead to the development of a

constructed social group which moves away from strong ideals about medicalization.

Before the 1990s, funding for breast cancer had come from private foundations; when activities demanded federal funding as their responsibility, this was reflecting a change in their thinking about breast cancer. Breast cancer did not need to be seen as a stigma, but as a problem due to insufficient knowledge of its causes and treatments. The government had not prioritised research into this disease, and as such an argument was presented that an epidemic had potentially been furthered due to institutional neglect (Kolker, 2005). The unacceptable rate of breast cancer was used to justify funding requests and the disease was redefined as epidemic of society and potentially environmental.

Both Kolker (2005) and Klawiter (2008) have discussed the development of breast cancer movements in relation to, and in comparison with, AIDS activism. A hidden argument surrounding AIDS research was that the government was spending more money on AIDS (seen as a male disease by activists) than breast cancer (coded as a female disease) and consequently the government therefore cares more for the former than the latter. The gender equity frame has been successful in the past, but this time was a period of conservative politics, so it may have been a difficult environment in which to launch such claims (Kolker, 2005). Klawiter argues that when AIDS entered San Francisco and the gay community, this group was already culturally cohesive and well-organised, as well as having political knowledge. Regarding breast cancer, incidence rates had risen but 'the omnipresence of breast cancer and the gradualism of its growth made it seem natural, inevitably, and timeless' (2008: 166). Also, it was found in all sections of society, unlike AIDS. Women were not already in a cohesive community, and whilst AIDS had identified lines of transmission between individuals, breast cancer had not and appeared almost randomly within populations. The gay community had been able to shape the ways in which AIDS was understood and represented: women with breast cancer were not in such a controlling position.

The ribbon is a symbol used to show awareness and support, and has origins in a yellow ribbon used in the early 1900s as a reminder of servicemen

serving abroad. AIDS activists made a red ribbon in 1991, red being seen as a colour of passion, and since then a ribbon has been used by many charitable causes (www.pinkribbon.org). The Susan G. Komen Foundation in 1991 gave pink ribbons to all the participants in its New York City Race for the Cure. The ribbon has never been copyrighted (for any colour) to allow it to be used widely as a symbol so no singular organisation could profit from its use.

The pink ribbon is arguably one of the most easily recognised charity brandings, and since the pink ribbon became the official symbol for breast cancer awareness month every October, it has created a platform from which ideas and behaviours surrounding breast cancer can be influenced. Whilst the pink ribbon is a generic symbol (meaning any individual or organisation can use it) it is also specific to a disease. One of the key researchers in this area, Gayle Sulik, argues that whilst the pink ribbon culture has achieved great things for the breast cancer community, there is the potential for detrimental situations to occur as a result of the culture and branding as a whole. To begin with, as anyone can buy into the pink ribbon, then anyone can reflect the identity of a warrior fighting bravely against breast cancer just by purchasing a pink item. Primarily within this idea, there is a key identity affiliated with the pink ribbon, and other pink products, which is available to individuals who consume the products available. Also within this is the idea that people who buy pink consumer objects automatically want to buy into the identity of a 'warrior'. There is this public awareness of a relationship between the pink ribbon, charities, and the idea of people diagnosed with breast cancer being warriors: as such there is a lack of space for members of the public to associate people with breast cancer with other identities. Identity is formed through social interaction and if the public are buying products in order to support a 'warrior' identity then people who do not fit this identity may feel that they are not publically considered to be meeting the perception of what a person with breast cancer should be like. The key discourse and set of imagery used within the pink ribbon culture (and arguably throughout the cancer industry) is that of the triumphant survivor, and these ideas and images are circulated in campaigns for both the mass media and public awareness.

Many people with breast cancer will not fit the idea of a 'warrior': they may see themselves in a different manner or feel that who they are does not fit this particular framework which has been set out by others. People are also more likely to act on things in which they believe, and feel good about. The pink ribbon has grown to be an iconic symbol and as such it reinforces certain beliefs. It also represents and refers to key American beliefs in, for example, scientific progress, optimism, generosity, and rising to a challenge (Sulik, 2011). Pre-conceived notions held within the pink ribbon culture can also be seen in other contexts. By actively advertising the pink ribbon culture, and associated relationships, as by women, for women, the disease is being more firmly entrenched as one which affects a certain 'type' of woman, a 'type' to which many individuals diagnosed with the disease will disagree, and find it difficult to respond. In order to take a road less pink there needs to be key changes in how breast cancer organisations are structured and how people perceive both themselves and others. Another consideration for the people purchasing pink products and donating money is to consider precisely where the donated money is going: is this going to be beneficial for all people, no matter what their breast cancer identity may be? If the money is going to a particular area which may not benefit certain people with a certain identity, there is the possibility that this could be detrimental to a number of people. It could be detrimental if people are put off by the overt femininity of the products, or perhaps the unnaturalness of some items, such as food which has been dyed pink. Consequently, potential funds may be going elsewhere, or possibly not being donated in the first place.

There is the possibility that the pink-ness, the quirkiness, and the overt femininity, detract from the seriousness of the diagnosis, as the pink ribbon culture is transforming breast cancer from a serious social problem, requiring complicated medical and social solutions, into a popular item to be publicly consumed (Sulik, 2011). People are able to purchase pink products, associated with breast cancer awareness and charities, and then display these products in an overt manner. Other people viewing these purchased items are at risk of seeing just the items and not the association with breast cancer, and as such their potential roles of raising awareness and funds may not be being met. As Sulik argues, the pink ribbon culture is aimed at encouraging people to feel positive and upbeat about breast cancer,

rather than to acknowledge how difficult and unattractive the realities of breast cancer may be. As a whole, the brand and culture rely on a collection of symbols and meanings in order to create and maintain the key message that breast cancer is a cause worth supporting, and that by supporting the brand, this indicates a good will towards women. Within the pink ribbon culture, 'optimism is displayed through hope and faith' (Sulik, 2011: 231) and there is an expectation of happiness and positivity, which perhaps requires emotional restraint on the part of the individual. Self-control in this sense is valued, but it takes effort to conceal pain and anxiety, thus reinforcing the idea that breast cancer is something about which people can maintain a positive attitude.

Breast cancer awareness and advocacy has developed greatly since its inception, and much money has been raised through breast cancer organisations through the pink ribbon. However, there may be reasons as to how the pink ribbon may have 'impeded progress in the war on breast cancer' (Sulik, 2011: 12): many people who participate in events each year are seen as smiling and positive, and these images are disseminated widely. However, this is not an accurate reflection for many of the women, and men, who do not fit into this pink breast cancer frame. For men, their sex means they are seen as outsiders straight away, and the association with the colour pink reflects many of the traits associated with western views of traditional femininity, such as childishness and emotional sensitivity and men may feel they need to portray such an identity in order to be accepted within the pink ribbon culture. This identity can be seen as the dominant identity used today by the pink ribbon culture as a representation of the breast cancer movement, but in order to obtain and maintain relevance, it needs to be more reflexive and responsive to the variety of individuals who have been diagnosed with breast cancer, and their supporters (Sulik, 2011). As such, there ought to be images and conceptions which are broader than the ones commonly portrayed today.

There are ways in which the pink ribbon culture can be viewed in which the feminine and masculine are combined: the masculine is seen within war metaphors, people being survivors, courage, and strength. The feminine moves away from the war metaphor and favours ideals of nurturance and empathy. For these to be united, there is the idea of a 'she-ro', 'a feminine

hero with the attitude, style, and nerve to kick cancer's butt while wearing 6-inch heels and pink lipstick' (Sulik, 2011: 16). This is still an idea which alienates men diagnosed with breast cancer. Whilst such a conception of a 'she-ro' may indeed include traits viewed as masculine, men still have to engage with feminine conceptions (wearing high-heeled shoes and make-up) in order to become part of this identity group. This seems less inclusive of different identity perceptions, and more exclusive only for those who are prepared to meet a certain ideal.

It is unlikely to be just men who are excluded from such an ideal; women may feel alienated, or in some way stigmatised, if they do not think they can live up to this ideal of being aesthetically pleasing in terms of being a breast cancer survivor. The use of wigs, prosthetics, and tattooing (if nipples have been removed) may help women to maintain an identity which fits with commonly accepted ideas of femininity, and help allow their bodies to remain as 'normal', but this is something with which men in particular will struggle, given that their body pre-diagnosis was 'normal' but in a masculine sense. If winning the war on breast cancer is viewed in terms of keeping the pre- and post-treatment bodies as similar as possible, then men may be at a disadvantage. However, masculine traits are involved in terms of how the ideal of breast cancer survivorship is created: to survive, and be a survivor, there is a necessity of selfishness, which is formed of perceived traits of masculinity such as having a 'rational coping strategy' (Sulik, 2011: 230). This ideal of being rational, the logic involved in a strategy, and the assumption at the start of breast cancer treatment that the individual will be able to cope, is entwined with ideals held within assumptions of masculinity, and that to engage with such a strong position at the beginning sets the individual up for the duration of their breast cancer experience.

There are groups and charities who are specifically trying to move away from the pink nature of breast cancer awareness campaigns. For example, Out of the Shadow of Pink is a website dedicated to moving breast cancer in men away from the overbearing shadow of pink, and with what pink is associated (www.outoftheshadowofpink.com). The site states breast cancer is a serious disease, especially if people are unaware that they could be diagnosed with that form of cancer, as it is considered to be a disease for women. The site has grown as an advocacy group of and for men diagnosed

with breast cancer. The products sold in the shop are pink, to retain the link with the wider breast cancer community, but they also have an element of blue, to reflect how men too can be affected.

In a similar manner, a website about breast cancer in men based in Canada was founded in 2008 by two women following their father's breast cancer diagnosis, and it aims to provide information about breast cancer in men as well as offering support. Their mission is to increase awareness and a goal to help with this is to establish the third week of October every year as male breast cancer awareness week globally. The site offers a ribbon for sale which is half pink and half blue, to represent that breast cancer is diagnosed in men as well as women.

The intersection of hegemonic masculinity and hegemonic femininity

As has already been shown, breast cancer is seen very much as a disease of women. It has been positioned and normalised in such a way that people in general are able to participate in events which appear to celebrate femininity, and what it means to be a woman. Men are encouraged to participate within this feminised environment, acting as supporters for the women. This tends not to be problematic, as men are only temporary participants of this environment, for example joining in with a charity event, before resuming their normal everyday roles outside of this environment.

Breast cancer awareness campaigns and organisations embody many of the ideals associated with hegemonic femininity, namely following heterosexual ideals, being feminine and sensual, with a focus on sexuality. Men diagnosed with breast cancer are entering this area of hegemonic femininity, at the same time as they potentially are having to be removed from ideals of hegemonic masculinity. It is at this confluence of hegemonic masculinity and femininity that these men will find themselves following their diagnosis. As such, these men can be seen as marginal members of a community, finding themselves on the outskirts of one community, and yet not quite able to be assimilated into another. It is this idea of marginality which is the focus of the next chapter.

Chapter Two

Marginal men

Introduction and background

The previous chapter has demonstrated how breast cancer is viewed across the world as a female disease. This is in terms of the number of women diagnosed, in relation to men, and also in terms of the assumptions and behaviours associated with this, seen clearly in the 'pink' of breast cancer awareness charities and events. Women are encouraged to unite through events in order to raise funding and awareness for 'their' disease. In many respects, breast cancer can be viewed almost as a celebration of femininity, and what it means to be a woman.

As people go through their day, and interact with others, they are likely to engage with different social groups and events, sometimes being part of the majority group, and sometimes the minority. People have varying levels of engagement with different social obligations and occurrences, and as such it is expected that not everyone will be involved to the same extent. In some situations, this may not be seen as problematic, but for those in which it is, there may be an element of disharmony, and marginality.

The exploration in the previous chapter of hegemonic masculinity and hegemonic femininity showed that within Western culture, men are very much the dominant group within society, especially men who further embody elements of hegemonic masculinity such as physical strength and courage. By also positioning breast cancer as a female disease, it is therefore not a disease for men, despite the small number who are diagnosed with it each year.

As such, the men who are diagnosed with breast cancer find themselves removed from the majority group of trying to embody hegemonic masculinity. Bury's (1982) concept of biographical disruption shows how individuals are in a position to construct their identities following a diagnosis, but it does not provide an adequate framework specifically for

men diagnosed with breast cancer. An alternative theoretical framework is required in order to understand how men experience being a breast cancer patient.

By becoming ill, and having to engage with medical professionals, men with breast cancer are no longer able to perform the hegemonic ideals of being physically strong and healthy. They are now part of a minority group, a minority that not many people even know exists. Whilst being a minority group to the majority group of healthy men who are embodying hegemonic masculinity, the men are a minority group in terms of breast cancer patients as well. The significant majority of people within this group are women, and as such they are dominant in the area. Men are viewed as strangers, as they are uncommon and unexpected in this area, both in the view of the women in the majority group, and in the eyes of the medical profession as well.

The 'stranger' was defined by Simmel in the early 20th century as a person who is a member of a system, but not strongly attached to it (Rogers, 1999). This idea influenced the value of objectivity in social science research: because the stranger is not rooted in the group, he can be objective towards the particular behaviours of the group. Alongside this objectivity is freedom, as the stranger is not bound by any roots from the group which could influence his perceptions and understanding (Simmel 1972/1908).

The stranger is a member of the group in question, but is not strongly attached, and is not in a position to completely conform to the accepted norms of the system. There is an element of distance in terms of interpersonal relationships, as someone is close, and yet also far away. The person can be a member of a group in terms of one characteristic, but not a member in a social sense. As Simmel (1972/1908) explained, whilst a stranger may be seen as meaningful to the group, as long as he remains a stranger then he cannot be seen as belonging. Strangers are viewed with suspicion by other people as the behaviour of the stranger is unpredictable and uncertain. Whilst a stranger is fixed within spatial boundaries his position is affected as he does not truly belong in it, as he has attributes which do not naturally fit in with it. Alongside this, social networks can limit the actions of individuals (Rogers, 1999) and as strangers do not have

these networks within the system, they are more easily able to deviate from the norms of the system.

This creates a foundation of sociological theory and framework which is ideal to use for exploring the experiences of men diagnosed with breast cancer. Marginal men as a theory builds on Simmel's idea of the stranger, and in terms of empirical research originates with the study of immigrants, as they try to belong to the culture of their new country. People in such a position have what Park termed 'double vision' in that they are seeing and experiencing what it is like to be in a marginal position, and also what is being undertaken by the majority group. By being on the outside and looking in towards the majority group, they are able to see the differences in the ways that things are done. This social positioning which is key to exploring and understanding the experiences of men with breast cancer: it is not just about the specific experiences of individuals, it is more about social worlds, and how strangers, as marginal men, are able to be key informants in helping develop understanding of how these social worlds are built, constructed, and maintained.

The experiences of a person with breast cancer are, to some extent, going to be unique to that individual, as people carry with them different experiences from past encounters in a variety of contexts, making that individual unique. However, the stories of individuals can then move to one of dimensions, of joined social worlds, and in turn, multiple reinforcement. The marginality that is experienced by men with breast cancer is a multiple marginality, due to the different social worlds that have different conventions to exclude them and make them more marginalised. For example, men may be marginalised through treatment options, due to the relative lack of medical information available on the disease in men, and then may be marginalised in a different way from a support group, as well as through the provision of support and care which could be undertaken by both friends and relatives as well as paid workers. Therefore, in many ways, men are excluded from various aspects of social worlds and contexts associated with, and surrounding, breast cancer. By not being women, they are viewed as being an 'other' and consequently, a stranger.

This chapter explores and critiques Bury's concept of biographical disruption, and demonstrates how it is not suitable for researching the experiences of men diagnosed with breast cancer, and how these experiences are to be understood. Park's idea of the marginal man is suggested as a more suitable approach, as it reflects how men diagnosed with breast cancer find themselves in a world which is fundamentally contradictory, and how their privileged position allows them to see the mechanisms through which they are less able to participate within the breast cancer community. This is broadened further by Star, who shows how objects and events create inclusions and exclusions, by developing standards within the social world which can lead to rigidity and being unable to incorporate the deviant case.

Biographical disruption

This thesis aims to explore how men experience being a breast cancer patient, and how these experiences are to be understood. Men diagnosed with the disease move from being an observer of the breast cancer community, to trying to participate within it. This requires an element of transition. One concept used to explore this idea of transitioning in order to incorporate a medical chronic diagnosis is Bury's (1982) biographical disruption, developed through research in individuals with rheumatoid arthritis. The emphasis during the research was concentrating on patients who had an emerging illness in order to explore changes in biographical features influenced by the diagnosis. Previously, there had been two main approaches to chronic illness, Parsonian ideas of the sick roles and interactionist accounts. However, chronic illness prevents some of the sick role assumptions from occurring, and interactionist accounts arguably had too much emphasis on empirical research rather than theories. Bury uses Giddens's (1979) term 'critical situation', in which we can learn a lot about everyday situations by researching circumstances in which those situations have been disturbed. Bury argues that chronic illness is exactly the kind of experience where everyday life is disrupted and it involves recognising pain and possible death, which are normally only seen as affecting others. The importance of researching illness narratives is that exploring chronic illness may show disrupted experience and their meanings, as well as action(s)

taken and may also reveal other issues such as links between identity and experience (Bury, 2001). Illness, especially chronic illness, is an experience which disrupts the everyday routines of life (Williams, 2000: 43), and patients have to pay attention to bodily situations which may not normally be considered, and make decisions about seeking help. Patients also have to consider questions about their biography, as well as look at resources available, such as social, financial, and medical.

By their very nature, chronic illnesses need to be managed on a daily basis: the consequences of illness can interfere practically in one's daily life but their dominant significance is in how they can undermine the everyday structures by which people construct and develop their narratives of self (Reeve et al, 2010). The key assumption within the biographical approach is the impact of illness on personal meaning, how it disrupts people's assumptions about the world and also their self and the future. As Bury (2001) argues, there are a number of narratives which can be employed by an individual with a chronic illness. There are contingent narratives, which are aspects of the story of the patient that are concerned with factors influencing the illness, symptoms, and immediate effects. Moral narratives form around valuations 'as sufferers seek to account for and perhaps justify themselves in the altered relations of body, self and society brought about by illness (p. 274) and perhaps trying to examine if there are coincidences between, for example, life events and symptoms. Core narratives are found in every account, such as tragic/comic, and romantic, and by employing these 'core narratives, people can both account for events and give shape to them in terms of the way in which they feel they relate to self and others' (2001: 279). Self-presentation may be conscious or unconscious as a process in terms of core narrative, but it is important to consider that these core narratives are available as a way of expressing their experiences. As illness is representative of change, it therefore constitutes a threat to an individual being able to maintain a coherent self. As such, illness can be seen in this way as a disruptive event (Reeve et al, 2010: 179). The use of the word 'disruption' implies that there is a state which is 'normal' or at least non-disruptive. From the research conducted by Reeve et al, disruptive narratives ('why has this happened to me?') were apparent 'but threats to narrative self-identity were transient events, and usually put to one side rather than resolved' (2010: 190). They theorised that there are two ideas of

biographical experience, fracture and flow. The fracture group had more of a sense of meaning which was disrupted. The emphasis was on how they needed to have the energy to keep going. Consequently, continuity can be maintained by efforts to maintain energy.

One route to researching how men conceptualise their health experiences is through illness narratives following a specific diagnosis. Solimeo (2011) researched such narratives of men diagnosed with osteoporosis, a condition in which bones become weaker and more prone to fracturing. It is also more commonly diagnosed in women who are post-menopausal. Here there are cultural ideas about weakness and vulnerability. Post-menopausal women are often seen as old and frail, and this fits with the illness as being one of frailty. Its conceptualising in this sense is at odds with the dominant ideals of men as being strong and firm. Consequently, 'men who are diagnosed with "women's diseases" contend with a complex set of social demands as they come to make sense of their somatic condition and limited treatment options' (Solimeo, 2011: 185-6). Bones on their own do not have an embodiment which is particularly gendered one way or the other, unlike breasts for example, but by sexing a disease such as osteoporosis as a female disease, this contributes to the suffering of men during their illness experience (Solimeo, 2011) as they are finding they have additional problems to overcome, such as finding a way to still portray themselves as masculine.

One of the key challenges is for public knowledge to develop so diseases are not so strongly considered as diseases solely for men, or women. Considering Solimeo's study, the men within it who had experienced early bone loss often did not consider that they would be diagnosed later with osteoporosis, as they viewed it to be a disease of women, and as such men were not vulnerable to receiving such a diagnosis. Taking this further, even considering men could be diagnosed with it, there was an assumption held by a few men that osteoporosis could not be life-threatening, as they knew of women who lived with the condition, and therefore by applying cultural concepts of femininity and (lack of) strength, it could not be that severe as otherwise these women would not be able to cope with day to day life with the illness. It is 'precisely the sexing of [osteoporosis] as a women's disease that ultimately serves to give men a false sense of security, decreased access

to care and treatment, and poorer outcomes' (Solimeo, 2011: 189). Such a false sense of security and perceived immunity could have led to a late visitation to a medical professional, and delayed diagnosis and treatment, both of which could have negative implications for the rest of the illness trajectory.

As men began to come to terms with being diagnosed with a disease associated with women, they encountered a number of ways in which the disorder was sexed, for example in the lack of data specifically focusing on men (Solimeo, 2011). Due to perhaps a lack of prior involvement with their health from a management perspective, men diagnosed with osteoporosis now have to follow a regimen which limits their activities in the hope of lowering their risk of causing a bone fracture. Following advice can be seen as passive, as men are having to accept that there are limits to what they now should do in order to prevent damage to their body. Passivity is a trait associated more with women than men, thus meaning men diagnosed with osteoporosis have a challenge on two fronts, that of challenging their ideas as to what is now to be viewed as 'healthy', acceptable behaviour, and how this can be incorporated into their identity whilst still allowing for masculinity to remain. After diagnosis, men found there was a tension between their masculinity and physical ability, and the expectations held by other people of their performance as men (Solimeo, 2011). The limited information available for men can be seen as a hindrance, rather than helping them to monitor their condition and lower risks. If the majority of information available is aimed at women, following research with women and experience of treating women for a number of years, this cannot just be transferred over to apply to men. Men diagnosed with osteoporosis may be finding this already challenging, and if they are being told information which is not proven to be relevant or applicable, this may just add to the confusion as to how they are to incorporate their illness into their identity. As there may be much more information available for patients than was previously available, so lay people know about more about possible treatments and options (Bury, 2001) this may have an additional consequence of adding to insecurity and being unsure of appropriate courses of action.

A critique of biographical disruption

The concept of biographical disruption is still seen as an important point of reference with regards to the sociology of chronic illness, but Williams argues it needs rethinking in terms of its nature and also for the future of sociological research in this area. There needs to be a consideration of whether biographical disruption is confined to chronic illness, as it is understood traditionally, or if they are features of a late modern society which has a reflexive order. Bury's concept has championed lay perspectives and experiences, and in doing so has been able to articulate the concerns of individuals who might otherwise not have been heard. However it does focus on an adult-centred model: most chronic illnesses do occur in later life but there is a neglecting of childhood conditions such as congenital abnormalities. The concept of biographical disruption 'rests on problematic foundations concerning the 'shattering' of our taken-for-granted assumptions about our bodies, our selves and the world in which we live' (Williams, 2000: 60) but illness may already be part of an individual's life, e.g. from birth, or because of events which are seen to be expected such as in later life. Alongside this there is also the argument that biographical disruption is felt more keenly by the privileged groups in society.

Bury's concept of biographical disruption focuses on how individuals may need to alter their biographies and conceptions of themselves following a diagnosis of a chronic illness, in areas such as incorporating medical care and support from relatives into their new daily routines. Whilst this can be seen as applicable to numerous chronic illnesses, contained within it is an assumption that this reconstruction of identity is at all possible in the first place. Reconstructing one's identity will be partly dependent on the resources available, such as social, financial and medical. For a woman who has been diagnosed with breast cancer, and for people diagnosed with other illnesses, such resources may be relatively easy to obtain, but less so for people who have illnesses which are more uncommon. As breast cancer in men is a rare disease, the medical information known about it is relatively little, compared with women, therefore the information needed by the man in order to help him start his reconstruction may be lacking. Equally, as there is little public awareness about the disease the social support available may not be as great as what is needed.

The varying narratives used by individuals to help the development of their biographical disruption may not be useful or applicable to men with breast cancer. A contingent narrative, which focuses on factors influencing the illness and immediate effects may not be of use because, as has already been discussed, medical knowledge about the disease in men is lacking meaning that it is hard to consider the immediate or long term effects of the illness and symptoms. Moral narratives share similarities with contingent narratives, as the paucity of medical knowledge means men may find it difficult to structure moral narratives around valuations: it would be hard to try to explore if there are any connections or coincidences between life events and symptoms. Whilst there is a lack of medical knowledge, which may make it hard to establish why or how the disease started, the rarity of the disease in men also means there is a lack of social assumptions or myths surrounding disease onset and as such the man may feel unable to position his illness in relation to a previous part of his biography, and perhaps 'make sense' of his diagnosis. A third narrative, that of core narratives, can be found to some extent in every account, narratives such as romantic, or tragic/comic, and when individuals utilise these narratives they are accounting for their diagnosis in a way which helps themselves and other people be better able to relate to the situation. For men with breast cancer, however, such core narratives may not be applicable, or at least not applicable in a way which enables people to still be able to relate to the self. The lack of knowledge or experience of how to act and interact in and around this disease may mean that core narratives are not most appropriate to the situation.

Biographical disruption involves an illness which affects one's identity, meaning that this identity therefore needs to be reconstructed, taking into consideration this diagnosis. Within this concept is the assumption that it is perfectly possible for this reconstruction to occur. However, whilst this assumption may prove accurate for many illnesses, it is less applicable and obvious for men with breast cancer. Such men find themselves, following diagnosis, in a world which is fundamentally contradictory. It is a world aimed at treating and supporting women, who are the dominant majority group, and men as a minority group have to find a way of joining in with this new group. This is made harder by the lack of awareness and

knowledge about the disease in men. From this, it is apparent that the assumption that people are able to reconstruct their identity is not applicable with such ease in this area. Men with breast cancer are placed in a marginalised position, a position in which they are in two social worlds, but not fully a part of either.

As such, Bury's concept of biographical disruption, whilst being a useful theory within the sociology of health and illness, does not provide the analytical tools required in order to understand how men with breast cancer construct their identities following diagnosis. What is required is a theoretical framework which will allow for an understanding and exploration of the situations men with breast cancer may find themselves, and how men as a marginal minority group are able to reconstruct their identities alongside the majority group of breast cancer patients. It is to this focus on marginality, and theories of marginalisation and being a marginal man, that this chapter will now turn. The work of Park and his conceptualisation of the marginal man is explored in terms of how it is appropriate for exploring men's experiences of breast cancer, especially when positioned in terms of what it provides that the idea of biographical disruption does not. This conceptualisation is followed through the Chicago School, leading to the work of Star who broadens the idea of marginality to include objects and events as well as people. The idea of being uncommon (as shown through men diagnosed with breast cancer) is shown as a response to actor-network theory, which does not account for the excluded, and how the standards of a social world produce inclusions and exclusions, which are understood by those in marginal positions.

Park and his work

Events of the early twentieth century, such as urbanisation and mass immigration, were entwined with the work of W.I. Thomas and R.E. Park, the latter being an investigative reporter who was brought by Thomas to Chicago (Fisher and Strauss, 1978). Individuals and their social relationships feature heavily throughout his work. Park (1936) used terms from ecology to create what is known as human ecology, the study of the relationships between humans and their natural and social, as well as built, environments. With E.W. Burgess he developed the idea of urban ecology,

and using the city of Chicago as an example, they posited that cities are environments just like those found in nature, and as such they are governed by many of the forces of evolution to be found in ecosystems. The basic pressure underlying social relationships is competition (Marshall, 1998) which is created by groups fighting for resources such as land, which lead to the division of urban space. In certain areas, people have the same social characteristics as they are subject to the same ecological pressure. Due to human interdependence from the division of labour, competition always has to involve elements of unplanned co-operation, and as a consequence of this, people eventually form symbiotic relationships, at the spatial as well as cultural level.

Park was sure that societies and cultures would always undergo change as they progressed forward, and entwined with this was the potential for progress to always be seen as problematic. The struggle for space results in conflicts between groups: urbanisation meant increasing antagonism between ethnic groups as they struggled to find their place in the city and these groups broke down further as the individuals began to regroup according to their occupation in different areas of the city. Park had faith in the relevance and success of empirical research, and he managed to move sociological research away from the 'social problems' research which had up to that point inspired most empirical research. His 1921 book 'Introduction to the Science of Sociology' encouraged people to look beyond an internal analysis of current American society and instead connect observed social phenomena to contacts between races and cultures, to urbanisation, and to development of the division of labour, processes which were appearing nationally and internationally. During his time spent studying race relations with Booker T. Washington in the American South, his main interest had been on the system which had developed and evolved to define relationships between black and white people in the South. He learned how deep-seated social institutions can be, and how difficult they are to change.

As Fisher and Strauss (1978) state, Park referred to an essay by William James in which he defined a type of blindness in people, referring to people's inability to see behind the masks other people are wearing. As such, people are blind, and unaware of their blindness. Group life and

associated customs ensure this, and it is only when people move away from their traditional life that they can confront strangers as individuals. Park thought that if people knew what was behind the masks then they would be naturally sympathetic, as he relied on a combination of compassion and knowledge. The problem would be in understanding how the person had been shaped by the group. As a consequence, Park was optimistic overall in terms of social reform.

The research conducted at Chicago between 1920 and 1935 can be characterised by a tension, which is also found at the centre of Park's research (Chapoulie, 1996). This considers the opposition between the moral order (which arises in competition between people) and the ecological order (which arises from competition between populations). The first addresses the subjective dimensions of social facts and how through collective activity meanings are produced. The second examined the objective dimension of social facts and how these appear in the process of evolution globally (e.g. the distribution of ethnic groups) and these can be understood by using statistics and maps. Park's image of sociology was focused less on arguing for scientific legitimacy (Fisher and Strauss, 1978). Private philanthropy was supporting sociological research so educated elites no longer had to be convinced as to the legitimacy of the value of sociological research.

The development of the Chicago School

The theoretical base for this research focuses on the work of Park (1928) and his concept of the marginal man. In order to understand how this concept developed, it is necessary to consider the Chicago School, as Park was one of its exponents. A 'school' in the social sciences can be thought of as similar to the term used in the history of art, to refer to a group of a group of people who share styles and techniques, and also have a high level of interaction with one another (Blumer, 1984). A school also implies that there is usually an affiliation to an academic institution and a way to publish research, for example a journal. The Chicago School tends to be viewed as a particular period with particular professors, students, and work produced, and roughly covers the period 1915-1935. It is something which exists between individuals: it was through the process of faculty interactions that

there emerged and evolved the tradition that is now known as the Chicago School (Abbot, 1999). The principal features of the Chicago School were its commitment to leading and developing empirical research, as well as its diversity in terms of methodology, rather than focusing on a given form of sociology (Bulmer, 1984). The Chicago School thought that in order to understand social life, there needs to be an understanding of how social actors are arranged in social contexts at particular times and places (Abbot, 1999) so social facts do not make sense away from their social context. The experiences of individuals need to be considered within their historic time frame in order for there to be accurate observations of social phenomenon.

Often considered leading figures within the Chicago school, W.I. Thomas and R.E. Park shared a commitment to empirical research, and a hallmark of the Chicago school is the integration of both research and theory into an organised programme (Bulmer, 1984). As Bulmer (1984) writes, *The Polish Peasant in Europe and America* (Thomas and Znaniecki, 1958/1918) was an empirical monograph, using personal documents, and showed new methods of conducting social research which were distinct from, for example, the social survey movement. By utilising new methods of social research, and by combining theory with data, there was a base for generalisation and to move forward sociology. The focus on the immigrant allowed sociology to be strengthened as an academic discipline, considering the changes occurring in American society with regards to increased immigration and urbanisation. The work of Thomas (*A Polish Peasant*) encouraged Park and Burgess to undertake empirical research of human individuals rather than using only official data or informants. This highlights the importance of how actors define a situation (Bulmer, 1984), as official data or second-hand information may not yield all the relevant information a first-person account could: how one person defines a situation may be remarkably different from the definitions given by another. The work of the Chicago School has a particular stance, it is processual and examines, among other things, organisation and disorganisation, and social movements and cultural change. Society is seen as groups and interaction, and not just individuals who are independent. The School reflects methodologically diverse approaches, yet retains a focus on empirical and often observational methods (Abbot, 1999). It is these observational methods which form the basis of the concepts addressed here.

Thomas' interest in the immigration of Europeans developed in context of, for example, the concern of social problems, reform, and other influences such as Upton Sinclair's *The Jungle* (1974/1906). The approach Thomas took, though, was scientific and detailed and highlighted a desire to try to understand human behaviour rather than just the desire to change society. As such, the study of social problems was made more scientific (Bulmer, 1984). Arguably, an approach that aimed to understand human behaviour would have wider and more applicable consequences than a narrow focus on one negative aspect within society. The ideas of Thomas and Park regarding social reform has implications as to where, when and how social change occurs. The when element requires group encounters and conflict, and the where too depends on these encounters. For Thomas, the how was through education and building institutions (Fisher and Strauss, 1978). Here, the foundations are laid for a focus on groups and how people need not be viewed solely as individuals.

Marginal men in the work of Park and Stonequist

Park perceived sociology as involving the analysis of the wider picture, to find out what is happening in the world, and to communicate this to other people in an overall quest to understand human nature. In a sense, this quest is universal. Park argued that class dominance was supported by the wider perspective of those in the dominant classes, and if people want to see the broader picture then they need to move away from traditional viewpoints. The term marginal man refers to an individual who is in several social circles which intersect: the marginal man cannot break with his past and is not accepted by the outside world: the marginal man lives within two cultures, and has nostalgia for the old culture alongside a developing attachment to the new. It is this duality of cultures which produces a duality of personality, and therefore a divided self. This is not a matter of simply adjusting how one sees oneself, but how one sees one's selves (Golovensky, 1952). All people may experience periods of transition at some point, but for the marginal man this period is likely to be permanent. Park surmised that it is 'in the mind of the marginal man that the process of civilisation is visibly going on, and it is in the mind of the marginal man that the process

of civilization may best be studied' (Park, 1928: 881). Marginal people may have the greatest potential for leadership, because of their special viewpoint and this marginality can be a source of creativity, intellectually and spiritually (Shils, 1996). Whilst social space is necessary for there to be social relationships, there needs to be a point of orientation in order for there to be progress. A potential leader must have roots in order to be able to relate to others, and in relation to marginality social space and a social location are prerequisites for a social relationship. Leaders need to understand their followers in order to be effective, and need to be educated and sufficiently integrated for this to occur (Fisher and Strauss (1978).

Whilst people may have used the concept 'marginal man' as interpreted to refer to ethnic minority individuals who may have personal disorganisation, Park viewed it as a concept which was more complicated, as a marginal individual is likely to be critical and alert, and often a leader within cultural organisations (Wacker, 1995), although the idea of a marginal man was a turning point within racial theory as it moved away from thinking solely biologically (Green, 1947). Park's work formed a base for the work of Stonequist who focused on immigrants and how individuals had the opportunity to become part of two or more distinct cultures. However, if the individual fails to successfully become a member of these cultures, then they are marginal and they have found themselves on the margins of each culture but without being a proper member of either. This marginal personality is seen most clearly in people who have becoming initiated into at least two or more languages, historic traditions, or moral codes (Stonequist, 1961/1937).

Participating in different social worlds and cultures can cause multiple personalities to arise, and it is this which results in the experience of being marginal. Different social worlds and groups may require varying elements of one's identity, and as such it could become problematic to maintain one fixed personality which can be used universally. Using these points, men diagnosed with breast cancer are definitely a marginal group, in terms of them being marginal from both other men regardless of health status, and women within the breast cancer communities. There are several ways in which people can access their selves, and '[a]ll of these ways of gaining access imply listening, rather than talking on behalf of. This often means

refusing translations – resting uncomfortably but content with that which is wild to us’ (Star, 1991: 30, original emphasis). There is an idea here within this quote that other selves are accessible, and that as such an individual has the potential to be assimilated further into a certain social world. There needs to be more dialogue between both social groups and the individuals who comprise them, as well as a realisation that some elements cannot be fully explained or manoeuvred from one social setting to another and as such there may need to be a process of acceptance rather than total incorporation.

There are differences between being assimilated in a cultural sense, and being a citizen: the latter can involve an economic contribution to a country, but there is still a disparity between this and complete assimilation (Stonequist, 1961/1937). Marginality is seen in the extreme in an individual who participates extensively and thoroughly in the dominant culture, but is still rejected (Green, 1947). Marginal man appears when group conflict is seen as a personal problem. A second-generation immigrant is likely to have the most problems as he is clearly where the two cultures meet. With regards to men with breast cancer, it is unlikely that they will become completely culturally assimilated within breast cancer organisations, as they are so strongly identified with women, both from the people within the organisations, and outsiders. However, as Stonequist’s argument posits, these men could make a contribution to such organisations without necessarily becoming completely assimilated. With reference to immigrants to America, if an individual wants to fully enter American society then, as well as making external changes, they must also feel and understand the American spirit and its thought and sentiment characteristics (Stonequist, 1961/1937). Stonequist argues that even immigrants with a European background will find transitioning to American society difficult, implying that even people from cultures that are similar to America, and with similar physical traits, may find inclusion difficult, as there are many factors to overcome.

Park (1928) posited that when individuals of different cultures and ethnic backgrounds come together, assimilation is likely to occur more slowly than with individuals who are of similar backgrounds. Potentially here there is the argument that men wishing to become involved with breast cancer

organisations are going to take longer to be assimilated into the main social group, simply because they are so different to begin with; other minority groups with breast cancer (such as younger women diagnosed with breast cancer, or women with breast cancer who identify as gay) may be assimilated quicker as they have more in common with the majority group to begin with. This is not something that men can overcome, as it is their gender which marks them out as different, and 'the chief obstacle to the cultural assimilation of races is not their different mental, but rather their divergent physical traits' (Park, 1928: 890). This can be seen as almost tautological; men may find it harder than other minority groups to assimilate in the majority group because of their physical trait of being a man. However, their reason for wanting to participate within this social world is their received diagnosis of breast cancer, which in itself is purely physical, and this is the common factor linking all members of this social world. Women in the minority groups mentioned previously may be able to smoothly assimilate based on their shared medical condition, whereas men's physicality is almost detracting from their diagnosis.

Park had a keen interest in what happened to country people who came to live in urban areas, as well as relationships between different ethnic groups and nationalities. Shils (1996) wrote that Park saw the moral order as having a collective self-consciousness. Using Park's example of black people (bearing in mind the time at which Park was writing), black people see themselves as black because of their skin colour, even though this colour pigmentation has no actual significance in terms of the collective self-consciousness. Children descend from ancestors, sharing the same colour, and this reinforces the significance of colour in the self-consciousness of that group. Shils argues this shows the strength of Park as a sociological theorist but then shows his weakness as he does not elaborate as to why colour is seen as significant by people. If it defines the difference between an in group and an out group, this does not explain why something as inconsequential as skin colour should be so consequential for humans. Park thought that assimilation was not perfect and that there are obstacles between accommodation and assimilation (Shils, 1996).

Park held the belief that relations between ethnic groups could be understood and hopefully improved through developing mutual

understandings between different groups, and also between individuals from these different groups (Wacker, 1995). Such a framework is arguably applicable with regards to breast cancer organisations and their members. Men diagnosed with breast cancer are currently seen as outsiders, as they form the minority group, and tend to have not had previous involvement in health care movements. Men will need to learn more about breast cancer and the support available, the same as any patient receiving a diagnosis. Organisations, and the women already involved in them, need to be aware of men potentially wanting to participate, and as such there needs to be dialogue between the two in order for both to have clearer understandings as to what is involved, and what is needed. Similarly, according to Park's ideas, prejudice is a reaction to attempts made by subordinated individuals to try to improve their status. Whilst this prejudice may be harmful, it also has the potential to inspire and mobilise group members and as such increase their sense of morale (Wacker, 1995). Because men diagnosed with breast cancer are a rarity, the majority group of women may unconsciously react in a perhaps negative way to men attempting to join in their events. These negative perceptions, whilst perhaps damaging to the men who wish to be involved, may also work as a catalyst in terms of mobilising action so that they can work together for a more positive outcome.

This positive outcome could be seen in terms of collective behaviour: Park thought behaviour could be seen as collective when everyone in a specific group is identified as being directed by a collective mood or as an impulse reaction from a specific interaction (Snow and Davis, 1995). Collective behaviour may be transitory, such as riots, or they may have more endurance, such as social movements. Park also argued that men and women can remodel the world through collective action, in terms of how their shared will and their broader collective aspirations recreate their social contexts (Park, in Hughes et al, 1952: 25). The implication here is that the individuals in social movements and organisations, by having a common aim or objective, are able to work together with the aim of achieving these. Breast cancer organisations tend to have specific objectives, and these require the co-operation of the people involved in order to, for example, raise awareness and raise money for continuing support and research. The inclusion of men within such groups should not be seen as a negative, as by

incorporating more individuals within the organisation, there are more people who can work together to try and succeed in the stated aims. As Park neatly surmises, '[i]nstitutions are, generally speaking, devices which come into existence in the effort to act collectively and exist in order to make collective action more effective' (in Turner, 1967: 23) and therefore it seems logical that an increased number of individuals actively participating with a named institution would be beneficial in terms of being able to reach stated collective aims. People are dependent and interdependent on people of various vocations and a 'social organisation is thus created in which the individual becomes increasingly dependent upon the community of which he is an integral part' (Park, in Hughes et al, 1952: 25). This presence of a society assumes a certain amount of consensus, common purpose, and solidarity. Park defined natural areas as a region which comes into existence without a specific design, and performs a certain function.

There are three phases involved in being marginal: in the first stage, the person does not have any internal conflict and is not necessarily aware of his group(s). He becomes conscious of the group only when he is aware that he is treated the way he is because of the group. In stage two, the marginality appears, as usual routines and attitudes may change due to changes in how he sees himself, as there are changes in personal conceptions. This has the potential to be a painful process, as the changes in how one sees oneself may not always have positive consequences or associations. In the final stage, the individual needs to respond to the situation; there may be a successful adjustment, but there may also be adjustments made which mean that in some respects he is still marginal (Stonequist (1961/1937: 122-3). The example given by Stonequist, bearing in mind the era in which it was written, is that of women who engage in work outside of the home – men may not want them entering their territory and women may be appalled by their apparent lack of conduct. There may be a strain between occupying two different social worlds (Star, 1991). Taking this idea and applying it to the exploration of identity with illness, with regards to men with breast cancer, a man at first is not usually aware of breast cancer generally. Following diagnosis and being to explore options, he becomes aware that he is part of a group due to the way in which he is treated by women with breast cancer and medical professionals. In stage two his routines and aspects of his daily life do have to change, following treatment and also how

he sees himself as he is possibly now identifying more with women. This has the potential to be a significantly painful part of the process, as how he had viewed himself before is not necessarily appropriate anymore, which requires a broad rethinking. In stage three, he responds to the situation, possibly getting more involved within breast cancer activism, or going public with his diagnosis and involvement, and this may be a successful adjustment to some extent. However, at the same time he is still marginal simply as being part of a minority group.

Within the overall idea of being a marginal man is the idea of a double-consciousness, in that individuals can see themselves from two viewpoints. How one sees oneself is developed by imagining how other people see us, and how they judge us based on this appearance. 'In the case of the marginal man it is as if he were placed simultaneously between two looking-glasses, each presenting a sharply different image of himself. The clash in the images gives rise to a mental conflict, as well as to a dual self-consciousness and identification' (Stonequist, 1961/1937: 145-6). There are issues here about how one may see oneself, and how this perception may change once the perceptions of other individuals are considered. In line with these reflections, people occupy many different areas at once, all of which involve the negotiation of various identities both within and across groups, and this is understandably a complex, delicate, and detailed undertaking (Star, 1991). How an individual sees oneself may be altered in light of how others see them, but also in terms of the context of the social group in which that person is currently situated. A sense of marginality can be powerful, as arguably each individual is marginal in some aspect. The power of marginality may be harnessed by marginal individuals to work towards aims and objectives which may benefit the dominant social group, or perhaps towards the establishment of a new social group for those who are marginal in this context.

Individuals are not seen as a marginal person until they experience the group conflict as a problem which is personal. To begin with, the individual absorbs the culture of the dominant group without thinking that they do not belong to it (Stonequist, 1961/1937). This idea of only becoming marginal once one realises one is not part of the dominant group is potentially visible within men diagnosed with breast cancer. It is likely that before he received

his diagnosis, he was unaware of the nuances of the social world of breast cancer organisations, charities, and support groups, and that only since his diagnosis has he become more familiar with how they operate and how they may incorporate practices which are unintentionally exclusionary. It is only since becoming aware of this that he has realised that despite sharing a breast cancer diagnosis, he does not belong in this particular social world. 'He was a man on the margin of two cultures and two societies, which never completely interpenetrated and fused' (Park, 1928: 892). Men are on the margin of their primary social world, that of being healthy men, as they have now been diagnosed with a serious illness, but they cannot successfully penetrate the new social world of breast cancer patients in general as they are on the margins in terms of being the minority gender. In a sense, men with breast cancer are perhaps almost a cultural hybrid, a combination of both social worlds but not really dominant in either. With the marginal man, feelings of inferiority arise from group situations in which he is made to feel uncomfortable, inferior, or perhaps even unacceptable (Stonequist, 1961/1937). This may lead to the individual withdrawing, which could ultimately prevent him from engaging in experiences which could change his attitude as well as boost his self-confidence. By virtue of being in an in-between situation, the marginal man may be in a position from which he can acutely and ably critique the dominant group and its culture, because he combines the insight and gained knowledge of the insider with the critical attitude learned by the outsider (Stonequist, 1961/1937). This knowledge has the potential to be powerful in terms of how the dominant group may be able to best achieve its aims, and whether it needs to consider the position of marginality if, for example, an aim is inclusion and equality.

It is possible that all people will have periods in their lives which are characterised by transitions and perhaps crises, but what is important for the marginal man is that these periods have the potential to be permanent (Park, 1928). Men diagnosed with breast cancer (or in fact, anyone with a serious illness) cannot necessarily go back to how they were before. Consequently, '[I]t is in the mind of the marginal man that the moral turmoil which new cultural contacts occasion manifests itself in the most obvious forms. It is in the mind of the marginal man – where the changes and fusions of culture are going on – that we can best study the processes of civilization and of progress' (Park, 1928: 893). By focusing on the marginal man, research can

hopefully illuminate areas of how culture changes and progresses. In line with this, as Star (1991) suggests, people develop new selves, some of which are labelled, and some are not. Some are unproblematic whereas others may cause anguish and the need to identify and unite with others, especially aspects which have the potential to dominate the entire self. This is arguably especially true for a severe chronic illness, such as cancer, as it can be seen to take over one's self and dominate much of an individual's activities and decisions. By focusing here on those who are perhaps more marginal, those who struggle to fit in with the dominant social world, processes surrounding inclusion can be highlighted, and how these may be transitory, short-lived, or how marginality may in fact be something with which the individual has to contend for longer.

Being a marginal man 'involves something of a problem, although it may elicit more amusement than despair, and stimulate rather than depress the individual' (Stonequist (1961/1937: 159). Marginal men may aim to be partially or completely incorporated into the culture which is dominant, and this does not necessarily have to be a negative process. Individuals may aim to 'pass' as a member of the group if complete assimilation is not possible, or indeed desirable. If assimilation is possible then the stage at which a man is marginal has the potential to be quite short. Equally, the extent to which an individual becomes assimilated within a group depends on many factors, such as age and the type of prejudice encountered (Stonequist, 1961/1937) and so different men will have different experiences which may influence how marginal they feel. Equally, assimilation is not always going to be possible and subordinate groups may always feel that they do not belong, even when they have taken on board the cultural nuances of the dominant group.

A critique which can be addressed to the marginal man concept is whether as a concept it is actually based upon a stereotype (Golovensky, 1952). Focusing on immigration, there is the assumption that there is one homogenous American culture to which people are trying to assimilate themselves, whereas this idea of such a culture may be an idealisation, or at least a reflection of solely middle-class values (Green, 1947). Whilst this is a valid observation, that arguably there may not be a 'dominant' culture as such, and that this may be based upon a stereotype, it is this stereotype that

individuals within and without of the group know of it, and it is this that they will use when considering their identity and their place regarding the group. As such, it is still a useful tool for conceptualising how people frame and develop their identities in relation to themselves and others.

Star

The work of Susan Leigh Star allows for the concept of marginality, as suggested by Park, to be developed and extended to include objects and events, as well as people, and to show how standards of a social world produce exclusions. Star originally worked under Strauss, but later became interested in science and technology studies (STS). Using data from late 19th century British neurophysiologists, she looked at how uncertainties encountered by scientists could be transformed into ‘scientific facts’, such as attributing certainty to research results found by other scientific fields, the generalising of case studies, and changing and evolving evaluation criteria. This demonstrates that standards do not exist in and of themselves, and so it is necessary to understand the relationship between knowledge, creation, and social worlds.

Star argued that scientific works requires different actors, and their different viewpoints. This creates a tension between the different viewpoints and the need for generalizable findings (Star and Griesemer, 1989). To explore this, she focused attention on one group of actors, people connected to Berkeley’s Museum of Vertebrate Zoology during its early years. The research showed that there are two key activities necessary for translating between viewpoints, the standardisation of methods and the development of boundary objects. These are objects which can be adapted by different viewpoints and yet are strong enough to maintain an identity across the different viewpoints.

As has been discussed above, there is a moral order of identity, of which people are accepting. These are structured, developed, and evolved through the actions of individuals within groups, communities and social worlds, and through the relationships of people who intersect with these communities. It is through a process of work that such identities appear. The meaning of

work needs to be understood in different communities in order for co-operation to occur (Bowker and Star, 1999). Anomalies arise when different communities come together, as different communities will have different interpretations of actions and reactions. 'Monsters' arise when that multiplicity has its legitimacy denied, when an individual learns that they are breaking a moral order and it is unacceptable for them to be part of another community of practice. Legitimacy is the endpoint of the trajectory of membership in a given community of practice, in that the overall aim of seeking membership, and to be accepted as a member, is to be able to view the situation as legitimate, and to be viewed by others as a legitimate member.

Work is seen through various indicators, and these indicators of work change according to the context, with context being seen as a negotiation regarding the relationship between visible and invisible work (Star and Strauss, 1999). Articulation work (from Strauss et al, 1985) refers to work that gets situations back on track when something unexpected happens, and is invisible to rationalised models of work. In order for articulation work to be successful there needs to be an analysis of the culture and politics of the work which it is to support. Feminist movements campaigned to have house activities such as cleaning and childcare redefined as work, in the sense of having economic value. This redefined the relationship between visible and invisible work. When there are broad structural shifts, as in this example, there may be large areas for debate. Work may be invisible to family and friends, such as the large amount of work that is needed caring for a family member with a chronic illness. As Star and Strauss (1999) argue, the context is important in analysing the visibility of work, for example prayer is a private action, many would not view it as public work, but nuns often say prayers on behalf of people in the community, this work is seen as being highly valued. People do not really see the circumstances in which a person works, partly due to the division of labour within manufacturing and production. What is an emergency for one person is routine for another (Hughes, 1970).

People who belong to more than one community are important for understanding more about the links that exist between moral order and categorisation (Bowker and Star, 1999). A focal question is how can people

retain multiple memberships, and the authors are dissatisfied with certain descriptions from social psychology, such as segmenting the self into compartments, or some type of multiple personality, as they portray each community of practice as ethnocentric and unwilling to accommodate any internal contradictions. Alongside this is also the idea of encouraging processes of assimilation on individuals, such as the Americanisation process of the early 20th century. Whilst marginality is sometimes nurtured, such groups usually exist anarchically, and are not institutional.

A key idea developed by Bowker and Star (1999) is that of borderlands and monsters. Drawing on the work of Haraway (1992) a monster occurs when objects refuse to be naturalised, and a borderland occurs when at least two communities of practice exist in one individual (drawing on Anzaldúa, 1987). Borderlands are naturalised homes of monsters known as cyborgs, and cyborgs are grotesque. An individual realises they do not belong in a community when what seems natural to everyone else appears to them as an anomaly. Such experiences as outsiders can develop into being monstrous in the collective imagination. History contains within it many examples of strangers being demonised. As classification schemes developed in science in the 18th and 19th centuries, monsters began to proliferate (drawing on Ritvo, 1997). They were seen as exceptions to natural laws, and united by their inability to fit with what was considered to be the normal. It is not just strangeness that matters, it is also the politics of the relationships and boundaries between and of the anomalies. A criticism of early sociological writers on marginality is that ideas were romanticised – this is not the case here. Communities of practice all have overheads and these can interact so one person (the example is of an old, black female) has a challenging situation of marginality, not just three demographic variables added together.

Star – on being uncommon

In order to examine the relevance of Star's work on being uncommon, it needs to be seen as a response to actor-network theory (ANT). ANT originated in the late 1970s and early 1980s as a practical sociological approach to the study of science and technology, and is associated with

Michael Callon, Bruno Latour, and John Law (see Callon, Law and Rip, 1986; Latour, 1987). These studies largely developed as accounts of 'science in the making' (Latour, 1987: 4) to challenge universal claims of knowledge by framing how it is actually created in laboratories. The key argument is that scientific knowledge is not objective and fixed but rather is achieved through the practices of association and translation between people, technology and nature. Scientific knowledge is the effect of this, and studies have focused on how scientific facts are viewed as unchanging. ANT has an interest in the durability of networks, and how they have to be worked at in order to maintain their stability.

As a criticism, ANT can be seen as less able to consider how knowledge is limited and how it is not positioned to be able to challenge the dominating structures within a network (Whittle and Spicer, 2008). It does not account for any structures which pre-exist the network and it could also be argued that the ANT perspective is descriptive and does not actually explain social processes. Specifically, ANT is not able to account for the people within the network who are excluded, and powerless.

Star develops the idea that marginality is not solely about people, it is also about objects and social worlds, and how standards work within these social worlds. When standards in a social world become rigid the deviant case indicates what happens when the standards of that social world become too rigid, and unable to easily include the individual who is different. These standards are not produced in a vacuum, they are developed through social interaction and take of values imposed through these interactions. Marginality cannot be seen solely as a form of an individual, but also as a way in which events are produced which replicate and reinforce this marginality. Men with breast cancer are excluded not as individuals, by individuals, but through the gendered practices and standards produced by the majority group. Standards produce exclusion, by having a 'standard' approach and therefore by definition a 'non-standard' approach. Such standards produce exclusions, and this exclusion is being between worlds. Subjugated individuals have a position from which they can provide a more adequate account of the world (Haraway, 1988) and are able to be more critical of these standards as they have a vantage point from which they are better able to view these standards and their productions in their entirety.

Minority groups are, by nature, unexpected, and as such they have the potential to be problematic. Star (1991) provides the example of her unusual allergy to onions, and how this can confuse orders given in a restaurant, especially a fast-food restaurant. These restaurants, with a very specific system in place for ordering cannot cope as efficiently with anything which is unusual. There is the potential for this idea to be applied to any large organisation, as minority groups in any context are going to be unexpected, especially if they are the minority in a significant number, or by a significantly different way. Star continues to explain how some people are reluctant to accept her unusual allergy. Applying this to the area of health and medicine, it is possible that even when men make public their breast cancer diagnosis, there are still people who do not believe them, simply because of the rarity of the disease in men. Relating this back to work by Hughes on status dilemmas and auxiliary characteristics, individuals need to portray themselves in a way which indicates they meet the 'unofficial', as it were, criteria for declaring themselves to be a person with this particular status.

Stonequist (1961/1937) argues that those immigrants who have published their stories are not typical of the average immigrant; perhaps because they have been more successful and this in turn has made them feel closer to a traditional American ideal, that of a man who is self-made. The process of publishing their stories creates recognition and this reinforces an identification with America. This is an interesting concept to apply to those men with breast cancer who have made their diagnosis public knowledge, to varying degrees. If the publication of immigrants' stories helped them identify with American citizens, and equally helped American citizens to view them as such, then men entering the more feminine world of breast cancer support and organisations may feel that being public and open about their diagnosis may help them to be seen as more included in this new group. Human interest stories in local and national news may go some way to highlighting the fact that whilst men will always be marginal, solely in terms of being a minority group and the relatively few number of men who are diagnosed with breast cancer each year, there are ways in which they can be involved with, and assimilated into, the dominant group. As Park explained (in Turner, 1967), the more the public understands about the

histories and attitudes of individuals, the more the public can know about the wider community. It is the context which is important as that shapes the people within it.

The context and wider environment are important as it is the context which guides interactions between people, and possibly presents limits and constraints. Using her personal example of being allergic to onions, Star (1991) suggests it may be easier for individuals to negotiate with producers who are less standardised, for example in a small restaurant, than in an international chain with a scripted system, such as McDonald's. It is this context which reinforces the marginality of a group of people. They are part of wider society in a broader context, and are able to engage with other aspects of an international chain, but they are limited with regards to food options. Even if every effort was made to include as many people as possible, it is arguable that there will always be the potential for there to be another marginal group, which would once again affect how this particular world will act towards them. Star explains how it is expensive to work within the contexts and constraints of one world, and practise outside of the set of standards it prescribes: as an extreme example, it would be nearly impossible to research advanced physics without the formal settings of a university or research institute. This highlights that there are numerous conventions in many areas, for example with reference to materials, measurements and standards. It is usual for items and individuals to fall within these conventions, and hard for them if they do not.

Arguably, men diagnosed with breast cancer are falling outside of the conventions of breast cancer communities. They are outside these conventions in that they are not women, but also perhaps outside another convention in that they are being pro-active and vocal about their health and involvement with a feminine-perceived organisation, which perhaps is going against the conventions of heteronormative masculine ideals in their society. However, these conventions are not consistently stable, and have the potential to change. Continuing with the example of McDonald's, it may provide stability for a number of people, but for people who are marginal to its systems, it is not ordered and is actually problematic (Star, 1991). From a research point of view, it is of paramount importance to consider these contexts within which people live their lives. Whilst society today is

immeasurably different from the time in which the first Chicago School theorists were writing, what is still important is how people may be constrained by broader social occurrences. Even if the social circles in which people find themselves are flexible and altering over time, it is the people who are on the peripheries and find themselves in potentially marginalised situations who have the potential to change what is seen as acceptable for a given social status or context.

Summary of conceptualisation of marginal man

Having followed the trajectory of thought and theorising through researchers concerning marginal men, this research project needs to be positioned within this history and evolution. Biographical disruption contains the assumption that reconstructing one's identity following an illness diagnosis is possible, whereas men with breast cancer are in a world which is fundamentally contradictory and they do not have the resources to approach this, meaning another theoretical framework is needed. The development of the Chicago School led to empirical observational methods, and the work of Park and the marginal man. The marginal man is in two cultures, and not fully assimilated into either, as Stonequist argued, individuals can make a contribution to a group or community and yet not be fully assimilated. Because of this occupation of two cultures, the marginal man has a double consciousness, and two viewpoints, a privileged position which other people within these groups cannot occupy. Star developed the idea of the deviant case, and what happens when standards used by a given social world become too rigid, as shown through her food allergy and fast food restaurants. Such standards have produced exclusion, resulting in individuals being between worlds: these individuals occupy a privileged position from which they can see beyond the rigidity of the standard in front of them. This develops the understanding of marginality, from a theory which is based on people, to one which is based on objects and the events people produce. Applying this idea to the research here, and how men experience being breast cancer patients, these conceptions and developments of marginality provide a framework from which the mechanisms through which men are less able to participate in the breast cancer community are articulated, and how standards produce exclusion,

placing men in a position from which they can see beyond the social standard.

Using the concept of the marginal man in relation to men diagnosed with breast cancer is where this thesis aims to make an original contribution to knowledge. As discussed in the previous chapter, first and foremost there is relatively little research conducted into men with breast cancer, due predominantly to the small number of men diagnosed. What research has been done has mainly focused on men as individuals, exploring how breast cancer affected them personally: France et al (2000) aimed to describe the social and psychological consequences of a breast cancer diagnosis in men, in order to help influence clinical management and service provision; Brain et al (2006) investigated the prevalence of psychological distress in men, and found that information needs are not being addressed; Bunkley et al (2000) found men may not discuss their illness with people outside of the immediate family and the study conducted by Thomas (2010) found that more awareness was needed, not just a case of replacing 'female' with 'male' in the literature, but targeting men specifically. The research for this thesis moves beyond what the experiences are individually for men with breast cancer, to focus on their experiences as a whole, and how these are to be understood, in terms of showing (through the experiences) the mechanisms through which men are less able to participate within the breast cancer community. It is not just about how individuals can influence the experiences of others, but how objects, how the norms, values, and standards of the social worlds created and developed by these individuals as a group can be seen as legitimising or restricting the access of certain individuals to this wider community. Breast cancer in men acts as a case study for exploring the relationship between one's gender identity and one's illness identity. The next chapter discusses the methodology for the thesis, in terms of how men's experiences of being a breast cancer patient are to be explored.

Chapter Three

Methodology

Introduction

The previous chapters have positioned breast cancer as an illness which is seen as a ‘women’s disease’, and outlined key ideas surrounding gender and masculinity. This chapter explains the methodological decisions made, and the path taken, in order to address the reasons and aims of exploring how men experience being a breast cancer patient and how these experiences are to be understood. Links are made between the methodological approach and the theoretical framework: discourse analysis allows for language and meaning to be explored in terms of how they are recorded and reported, and can help to provide depth and breadth in terms of researching the experiences of men, how they are vocalised, and how this is seen from the privileged position of Park’s marginal man. Discourse analysis as a methodological approach is discussed, and how it is appropriate for this research.

The three datasets for this research (interviews, media analysis, and forums analysis) are outlined in terms of the sampling strategies used and how the acquired data were analysed. Following a discourse analytical approach, the interviews were transcribed then coded by hand. For the media analysis, the large volume of data amassed meant it was more appropriate to analyse this using the qualitative data software tool NVivo. The sampled threads on the forums were coded in a similar manner as the interviews. The use of triangulation (using more than one form of data collection) can extend the integrity of the knowledge drawn from data, and therefore triangulation provides a more thorough understanding of what is being researched, which is especially important given the exploratory nature of this research study.

Reflexivity is taken into consideration, given the serious nature of breast cancer, and its emotive situations, experienced by those participating within this research. Ethical considerations are discussed, and the conclusion

provides a rational justification of the methods used throughout this research project.

How methodological approach links with the theoretical framework

The aim of this thesis is to explore how men experience being a breast cancer patient, and how these experiences are to be understood. The utilisation of discourse analysis allows for language and meanings to be explored in terms of how they are recorded and reported. In order to address the research question of how men experience being a breast cancer patient, and how this is to be understood, there needs to be a focus on how such men vocalise their experiences, and also how this is viewed and reported by others, who may occupy different social worlds. Park's idea of the marginal man positions men diagnosed with breast cancer as being able to see the world from different viewpoints, and using three sources of data, analysed using discourse analysis, means that these positions can be explored in terms of both depth and breadth.

In terms of the appropriateness of using such an approach, research on newspaper articles with regard to cancer has been conducted before, using similar approaches to the ones utilised for this thesis. Clarke and Robinson (1999) analysed newspaper articles on testicular cancer using a qualitative approach to content analysis, in which number counts were used as a context, meaning the manifest content of an article, such as the importance of early detection, was recorded, and then followed by a more focused reading such as the relevance of self-examination. This was in turn followed by a discussion of metaphors found within the text. Such an outline is similar to that used in this research endeavour, which also followed a path methodologically similar to that of Seale (2001a, 2001b) in his examination into stories presented in the media of people with a cancer diagnosis. His summaries opined that content analysis can help in terms of assessing how widespread a particular phenomenon may be, and discourse analysis is useful with regard to understanding the rhetorical effects which may be produced through the use of certain word, phrases, and themes within a given text.

Content analysis as a research tool focuses on the features of text which are apparent, rather than on any hidden elements (Ball and Smith, 1992). As it is firmly acknowledged that the frequency of any given category does not necessarily equal significance (Scott, 1990), this is a reason why content analysis was implemented alongside discourse analysis to be able to hopefully elaborate on results from the content analysis and so hopefully elicit where (if at all) significance resides. Whilst content analysis is to an extent subjective, as individual researchers may disagree as to the most appropriate coding for a particular element, but as will be discussed below, the use of NVivo allowed developments and progress to be followed throughout the process of analysis.

Discourse analysis as an approach

Following on from the theories explored in the previous chapters, discourse analysis is a suitable vehicle for analysing the data collected for this research. With regards to Bury's (1982) concept of biographical disruption, discourse analysis is a way of investigating language and studying meanings: as biographical disruption concerns how people incorporate an illness diagnosis into their identity this can be shown through the meanings held within text documents, such as newspapers and interview transcripts. Simmel's (1972/1908) concept of the stranger and its theoretical descendent of Park's marginal man are important as they have variables which may influence the way people communicate, which links to discourse analysis and its approach to communication.

The main strategy used in this data collection was that of discourse analysis: 'discourse' can imply any form of talk or text, as well as being seen as a pattern in 'ways of representing specific phenomena' (Lupton, 1999: 260) and discourse analysis can be described as 'a careful reading that moves between text and context to examine the content...and functions of discourse' (Gill, 2000: 188). Discourse analysis is by definition an interpretation, 'the analysis of language in use' (Brown and Yule, 1983: 1) and as such it is plausible that there will be multiple ways to read any discourse – it may be ineffectual to establish one version of the world when really several versions may be available. In essence, discourse analysis

involves asking questions about how language in a particular time and place can engage with areas such as social significance, individuals' identities and relationships.

Discourse analysis can be described as 'the study of talk and texts' (Wetherell et al, 2001: i). It is a method of investigating language within social contexts, and it is also a way of studying meanings and the dialogues which form social action. Hodges et al (2008) posit that discourse analysis is useful for researching a range of questions within health care and health professions as it studies and analyses how language is used. Discourse analysis examines a variety of factors including cultural themes, and observing these themes allows the researcher to have a deeper understanding of how individuals work within their framing of particular issues (Skillington, 1997). Discourse is more than language, is it a constitutive part of the social world which is a focus of interest (Bryman, 2004) and a discourse analytic approach is concerned with the way(s) in which knowledge is produced within a particular discourse, for example a medical discourse or a legal discourse, or through adopting specific theories in order to make sense of certain social actions (such as gender relations) (Spencer et al, 2003).

Discourse analysis is probably best viewed as a field of research rather than one particular approach (Bryman, 2004; Taylor, 2001). A common starting point is to look at language in use, and any associated patterns (Taylor, 2001). Language conveys meanings, assuming that the individuals involved within the discourse know the basis of that language. However, language is always changing, and as such language acts as a site in which meanings are created and also changed. As language is used for action, and for processes such as providing explanations, it is necessary to be able to consider the situated use of the discourse.

Researchers who base their work within a perspective of discourse analysis concern themselves with how different discourses are constructed and potentially altered. As such, they attempt 'to describe, understand and explain particular historical accounts and processes' (Howarth, 2000: 131), attempts which therefore allow a variety of research methods and styles in keeping with its ontology. As '[n]arratives...are created within a particular

context and for a particular purpose' (Barnes, 2004: 128), the aim of discourse analysis is an attempt to access these contexts and purposes which primarily enabled the narrative to be produced. Whilst discourse analysis focuses usually on case studies, larger inferences could be explored through further research (Howarth, 2000). Howarth goes on to surmise that discourse analysis grew in popularity partly due to the 'growing dissatisfaction with mainstream positivist approaches to social science' (2000: 1). Within this area, it is popular for a social constructionist stance to be taken. In an editorial for a special journal edition on health and media, Lupton wrote that all the writers who were featured saw 'knowledge about and experiences of health matters as being at least partly created through the media they analyse' (1999: 261), as seen through a particular focus on language and specific features such as metaphors.

Discourse analysts suggest that 'language is used for a variety of functions and its use has a variety of consequences' whilst also acknowledging that one phenomenon can be described in a multitude of ways (Potter and Wetherell, 1987: 35). This means that different accounts will display variation in the subject matter and it is problematic to find a single account which displays the highest level of accuracy. As such, investigating a wide number of newspaper articles this should hopefully illuminate certain key issues in this area which can be further explored.

As explained by Gee (2011) there are different approaches to discourse analysis: some look on at the content on the language that is being used, such as themes being discussed in a newspaper article, whereas other approaches focus more on the structure of language and how this function works to create meaning in a given context. Descriptive discourse analysis describes how language works in order for meaning to be understood. The hope is to gain deeper understandings as to how language or the world works, and why they work in that particular way. The approach taken by critical discourse analysts is that while there is a desire to know how language works, there is another desire to apply their work in some fashion, such as intervening in social issues. A criticism of critical discourse analysis from a descriptive discourse analysis standpoint is that it is unscientific as the analyst is influenced by their interest in a particular social issue. A criticism of descriptive discourse analysis from a critical discourse

analysis viewpoint is that it has evaded social and political responsibility as the focus is solely on the meanings within the language. Critical discourse analysis is commonly used within sociological research (Hodges et al, 2008) and has a wide sphere which includes social practices, institutions and individuals that make it possible to understand social phenomena in a particular way, and make statements about what is considered to be true. There is a particular interest in power, and this is where it links with the application of the research to wider social worlds.

Formal linguistic discourse analysis is the structured analysis of a text document, in order to find general underlying rules, whereas empirical discourse analysis does not have structured methods to look at individual words: the focus here is on broad themes and how language is used in action (Hodges et al, 2008). A third approach is to examine patterns in language associated with a given topic, and the associated terms and meaning, for example in certain jobs and industries (Taylor, 2001). Language can be seen as an important part of wider social processes.

Considering the standpoint of this research project, from an epistemological point the research is not trying to produce universal knowledge (positivism), but to suggest one interpretation which is admittedly partial. As argued by Taylor (2001: 12) it is hard to have one truth, as social science research involves people, who are likely to have their own view points. Claims of truth cannot be checked specifically because accounts people give of the world are not straightforward reflections of what is occurring. A discourse analysis is an interpretation, and can even be considered an interpretation of an interpretation, as the researcher examines discourses which are themselves an interpretative work people have done in a specific context (Gee, 2011). Referring to the action oriented approach to discourse analysis, this can be seen as anti-realist as it denies there is an external reality awaiting portrayal by the researcher (Bryman, 2004). It is also constructionist as the emphasis is placed on the version of reality as seen by members of that particular social world. There are different ways of seeing the social world and so a depiction of reality can be built by using these different ways. Discourse is not a neutral device: people seek to achieve something when they talk or write, and as such discourse analysis can be action-oriented, with the focus on a way of getting something done.

As has been shown, there are different approaches towards discourse analysis. This research study takes an approach which is a blend of these different viewpoints. This is done in an attempt to capture and understand the full complexity of the nature of the research study, which is complex in both its triangulation of research methods and its investigation of a medical diagnosis which is common yet rare at the same time. People often enact their identity by using discourse in such a way that a certain identity is attributed to others, an identity which is then compared with their own (Gee, 2011). Therefore, a question for discourse analysis is what identity/identities is this discourse being used to enact? For such a question a description approach can be used, to look at the language being used, and what this reflects. Identities are negotiated within interactions, as shown through the discursive action model (Horton-Salway, 2001). Further to this, there is the argument that all discourse analysis should be critical, as all language is political (Gee, 2011). There is almost a duty placed upon researchers in this sense to be able to apply their research findings and knowledge, to make use of it in terms of wider social or political issues. The blended approach to discourse analysis marries well with the triangulation of the research methods, as emphasis is on exploration, rather than explanation, and overall 'discourse analysis is a process of exploration and interpretation, and simultaneously, one of evaluation' (Taylor, 2001: 318) thus encapsulating the exploratory nature of the research study as well as the evaluation and potential for social action.

Sampling

Interviews

In qualitative research, non-probability sampling is often used, in which individuals are selected because they reflect certain features (Ritchie et al, 2003). This purposeful sampling is employed, so that individuals are selected due to their experiences of the key phenomenon (Cresswell, 2003) which will allow researchers to explore key themes and broaden their understanding. Whilst the people interviewed for this study can in no way be deemed representative of their contextual group, as they were selected for

study because of certain life experiences, it was this knowledge that was necessary for the research and therefore what they have to say is relevant in that regard. Some methodologies allow respondents to select themselves (Oliver, 2003) and as such they have time to consider their decision. Arguably it is better for the quality of the research to have respondents who are interested in the nature of the research and who are willing to participate. All the respondents for this research project had to ask to be involved. One possible alternative method would have been to use a snowball technique, and to recruit respondents through the social connections of the researcher and other respondents. However, whilst this may be possible for other studies, due to the small number of men diagnosed with breast cancer each year, it would be unlikely that in the researcher's world (and indeed, the world of the respondents) there would be such men available.

In their summary of interviewing men based on around one hundred qualitative interviews with men, Oliffe and Mróz (2005) opined that men rarely responded to advertisements which invited them to be interviewed about their health or experiences of illness. As such, a number of national cancer and specifically breast cancer charities were identified as potentially being able help with recruitment. From their websites, an appropriate person to contact was found, and a letter outlining the details of this research was posted to them, asking if they would be willing to help with recruiting men who had received a breast cancer diagnosis. Most charities if they did respond were positive with regard to the nature and aims of the research but did not have the resources available to assist with recruitment. Another reason given for being unwilling to help was that one charity wished to focus its efforts on medical research. One charity did however agree to be of support. After an initial email exchange with the gatekeeper, during which the specific aims and requirements of the research were addressed, an external researcher request form was completed and submitted. The most important part of this procedure was to show that the aims, objectives, and possible outcomes of the research, were compatible and in keeping with the aims and objectives of the charity, and the people involved with it. This approval procedure concerned proving the research had been ethically approved by the university, and the credentials of the researcher and her supervisory team. It also involved detailing the assistance desired of the charity and how the charity would be acknowledged in any publications,

whilst always being explicit that the charity is assisting the research, and in no way are they responsible or accountable for anything that arises from it.

Following an informal meeting at the charity's headquarters, the external research request form was approved. The research request form had stated that it was hoped both staff members and men with breast cancer could be interviewed about their experiences with breast cancer and the charity: it was hoped that the men could provide insights into their experiences of living with the disease, and their involvement with this charity (and charities in a more general sense), and that the members of staff could show how they viewed the charity, the charity sector, and the involvement of men with breast cancer as a minority patient group within a much bigger female majority group. It must be stressed that the interviews are the opinions of the members of staff as individuals, and not necessarily that of the charity. A concern raised by Oliver (2003), with regard to the involvement of organisations within research, is that respondents may work within a hierarchical structure and so may need reassurance as to the boundaries of issues on which their organisation would be happy with their commenting. This research project was approved by the gatekeeper, and to the best of my knowledge, no boundaries were given for the interview process.

Regarding the men needed for this research, the gatekeeper put a call for participants on the forums section of the charity's website. This consisted of a few paragraphs outlining the research and providing contact details, as well as emphasising the authenticity of the project. This information was posted in the forum specifically for men with breast cancer. Three men who had previously been diagnosed with breast cancer got in touch about participating. Of these three, two interviews were conducted in the home of the respondent. One was conducted over the telephone as the respondent was currently undergoing chemotherapy and due to his weakened immune system did not wish to come into contact with more people than was necessary. Interviews were longer than those with staff members, possibly due to the more personal nature of the experiences being discussed, and tended to last for around one hour.

This is admittedly a relatively small number of interviews, but was realistically the only method available for this research study. As the study

was not eligible for recruiting through the NHS, it meant men would have to volunteer in order to participate, rather than be recruited through other means (for example, being recommended by medical professionals with whom they came into contact). However, in relating it back to the ideas of discourse analysis, because the emphasis is on language, rather than necessarily the people producing the language, and because a large number of linguistic patterns are likely to be seen from relatively few people, this means that a smaller number of interviews is usually adequate for investigating a range of phenomena (Potter and Wetherell, 1987).

Regarding the interviews conducted with staff members, the charity gatekeeper produced a list of members of staff whom she thought would be able to answer the research questions, and also willing to participate. This list remained private. The individuals on this list were contacted by her; the email contained attachments of an outline of the external researcher request form; and possible interview questions. Contact details were provided and staff members were asked to make contact directly. Four members of staff did so, three women and one man. All interviews were conducted over the telephone. One interview was done so at the request of the respondent, and the other three were a matter of necessity – due to a number of factors, there was a very small time frame in which to conduct the remaining three interviews, and so they were scheduled on consecutive days in London, at the charity's headquarters. However, a personal injury meant that travel was impractical and so all staff members were interviewed by telephone. The length of the interviews varied, as there was an awareness that participating in this research was taking time out of their working day. On average, the interviews lasted for around 45 minutes. Interviews with all respondents were recorded and transcribed verbatim as soon as possible after the event.

Media sampling

To obtain a large number of articles, the Factiva database was used. This is a research tool which collects content from a wide variety of sources, allowing users to search this content, the phrase 'male breast cancer' was entered into the search function with the date parameters such as XXX-

31.01.2011. This date range was selected to cover a reasonable number of years, and to work in full months. This time period has been eventful in terms of breast cancer developments, as shown through various drug developments and trials, for example the legal battles undertaken by patients who were at first denied access through the NHS to the drug Herceptin. Events such as these meant breast cancer was often in the media. This time frame also showed the continued growth of breast cancer charities, and the range of charity events. These combined have all ensured breast cancer has had a relatively prominent place in both national and local newspapers, in a number of countries.

The Factiva database contains articles from English language newspapers – countries covered include the United Kingdom, the United States of America, Canada, Australia, and India, all countries which have English-language newspapers. For this search there were 2,319 publications found. The use of such a wide range of materials produced externally to the research ‘is helpful because it allows the researcher to capture the widest possible variation in accounts’ (Potter and Wetherell, 1987: 162). Some of these articles are duplicates, and the search results automatically highlighted them as such. Most of these duplicates were discarded – for example, if there was a national press release about a recently developed drug, which was printed identically in a number of national titles, only one of these was kept for analysis. If they were printed in different countries then they were kept in order to have some degree of comparison between countries. The reasons they were discarded is because they were verbatim – as this research is interested in the different stances and interpretations newspapers of different areas present, and human interest stories about male breast cancer, therefore a report of a press release does not necessarily reflect that accurately. Equally, articles were also rejected if they appeared in different editions on the same date – as these articles were identical it did not make sense for them to be included twice.

In a similar manner, because during the search the option was selected to include all documents (which were then sifted through to include only those of relevance) quite a number were discarded. These included long academic journal articles (as the focus of this strand of the research is on how male breast cancer has been viewed in national and local newspapers, which need

to be aimed at a lay, rather than a professional, audience). Because the search term 'male breast cancer' was used, and since it could not be narrowed down in terms of where in the article it was to be searched for, several articles were rejected because male breast cancer was only referred to in a secondary manner. For example, a number of articles were rejected because they only included 'male breast cancer' when referencing other articles the author(s) had written – the article which Factiva had located in this search had no other relevance with regard to male breast cancer and had only been included because of the search parameters. As these articles were not directly related to male breast cancer or to the aims of this section of the study, they were rejected.

Forums sampling

For this aspect of the research, an internet search was conducted for breast cancer online support forums in a number of English-speaking countries (the United Kingdom, the United States, Canada, and Australia). A number of forums from charities which appeared in the search results were then analysed, according to different themes. The forums all had sub-forums and it was these which were required: chosen for analysis were the ones that specifically had a designated part of the forum for men diagnosed with breast cancer. (Other sub-forums included different types of cancer, different stages of cancer, for family and friends of those with a cancer diagnosis.) In these sub-forums were threads, or discussions. In these threads, users could post a reply directly to one post, or they could add their post on to the bottom of a thread, meaning the whole thread could be read as a conversation. As with some other online forums, users did not always need to be registered in order to search or post messages on the site. In cases where users did not need to be registered, their posts would show up as being from an anonymous poster. If the poster was registered, then the post would show their registered username (which can be anything and does not need to reflect their real identity). For most of the forums, registration has the additional benefit of being able to send private messages to other users.

Data analysis

Interviews

Being able to interview men diagnosed with breast cancer, and people involved in a breast cancer charity, was seen as important for the research as a whole, providing as it did opportunities to understand meaning from the point of view of individuals, and to allow them to give their own accounts of their experiences. Whilst originally deemed to be the dominant data collection strategy, due to the relatively small number of men diagnosed with breast cancer each year, and therefore the likelihood of only being able to interview relatively few men, it was decided to follow this research method alongside the analysis of newspaper articles and online forums. It was hoped that this would increase the richness of the data, thereby providing a bigger resource with regard to meeting the aims and objectives of the research questions. Interviewing provides a way to generate empirical data regarding the social world through asking individuals to talk about their personal lives and experiences (Holstein and Gubrium, 1997). As respondents for this research were presented with the opportunity to discuss breast cancer in a way they found acceptable, this is reflective of an epistemological foundation through which information can become and be considered as knowledge when what is being used is the own ideas and language from the subjective experiences of the respondents.

Personal accounts of experiences are seen as important within social research, as language has the power to make meaning clear. Interviews focus on subjective experiences, and the people who have experienced certain situations (Merton and Kendall, 1946). With interviews, the research is seen as having an active role, in terms of structuring and guiding the interview process. In-depth interviews provide a combination of structure and flexibility (Legard et al, 2003). Topics can be discussed in a way which is suitable for the respondent, and responses can be explored as the researcher is in a position to ask further questions, and the use of probes and follow up questions can achieve depth in answers. This makes the interview interactive in nature, as the researcher can explore all the factors which may underpin the answers given by respondents. As Legard et al (2003) explain, the interview process is generative as new knowledge or

thoughts are likely to come through, and explanatory evidence is a key part of qualitative research. The interview guide produced by the researcher focuses on the major areas of the enquiry (Merton and Kendall, 1946) and there is the possibility that through the process of being interviewed, the respondent is perhaps exploring their experiences in a way previously untouched. This has the potential to generate new insights into the social world being investigated.

As Crotty (1998) argues, from a constructionist viewpoint meaning is not just there to be discovered, but is created as human beings construct meanings through engagement with the social world. A constructivist approach can emphasise the role wider communities play in terms of how people see and understand the world around them, and the ontological viewpoint for constructivists is that humans are involved in the constructions of their own world: as this world exists in separation from our senses, observers will perceive it different than both the person whose world it is, and other observers (Moses and Knutsen, 2007).

All the interviews were semi-structured in nature. The staff members had seen an interview guide, as a prerequisite of the external researcher request form, but it was made clear that this was only a guide. Using a semi-structured format within the interviews allowed questions to be asked which directly addressed the aims of the research, whilst still having the flexibility to react to remarks made by the respondent, and to develop in-depth points raised. Semi-structured interviews should contain dialogue which is interactional, be by nature informal, centred on a particular topic, or have a biographical approach (Mason in Hall and Hall, 2004). The biographical focus in these interviews on either the respondent's experience with breast cancer or their work meant they should not have been made to feel ill at ease due to a lack of knowledge. It was presumed (to an extent) that the respondents would be able to answer, in one way or another, the questions asked during the interview – this should hopefully have ensured a sense of ease, as the emphasis was not on (in)correct answers and instead on their own experiences.

In line with creating a reassuring atmosphere for the interview, the order of the questions was presented in such a way that more straightforward

questions were asked earlier on (such as recounting past events) before complex questions were asked (such as those investigating feelings, emotions, opinions that perhaps required an element of consideration). Whilst some participants did seem able to discuss emotive topics from the outset, this route of dialogue would be started by themselves, rather than the researcher. Alongside this, interviews attempted to be closer to conversations, almost, than interviews, to allow for a dialogue to flow. This was helped by telephone interviews, as the men were not able to see my list of questions therefore enabling it to seem more like a conversation. Equally, by emphasising a conversation and dialogue more than an interview, this meant that the patients' experiences were emphasised as being central to the study, and creating more balance between the researcher and participant, so that neither felt of passive, unequal, status.

Oliffe and Mróz used a sequence of interview techniques in their interviews with men, to encourage participants to talk freely, techniques which were also appropriate for the male breast cancer patients. Prompt questions such as 'what happened next?' allowed the men to describe what had happened and allows for the research to ensure that clarity of what is being said. It also acts to reassure participants of the validity and importance of what they are saying. This was followed by more probing questions, to encourage the men to reflect upon their answers and experiences. This also allows for men to go from talking about the disease more generally, to their diagnosis in particular. The interviews for this research followed the sentiment that the interviewer ought to hide personal opinion (Holstein and Gubrium, 1997) and the questions were asked in a way which hopefully did not direct the respondent to a particular answer.

A main concern with interviews is that they are not usually the context in which respondents would talk about the areas being researched – whilst people often talk about their work, their illness, their experiences, in a variety of formats, interviews are 'detached from the circumstances in which persons act' (Hughes and Sharrock, 1997: 129) and as such knowledge gained from the interview process may lack some validity. However, the question to ask here is what is the format in which respondents, the men with breast cancer in particular, talk about the areas discussed in the interviews? Focusing on the men interviewed, whilst they

have talked about breast cancer with their family and friends, the interview required a more story-telling biographical approach – as those close to them would have been through this part of the biography with them, such a formal account would be unnecessary. Similarly, the respondents would often have had to discuss their illness with health professionals, but as this research is not focusing on the medical side of breast cancer, and as not all the people involved in the interview interaction have the requisite medical knowledge, such a format is also arguably unnatural. Therefore, whilst it is an acceptable criticism to levy against the interview procedure that the dialogue produced is unnatural in its origins and format, it equally is an acceptable response to argue what an acceptable format would be, and if such a format would be attainable and still provide answers to the research questions.

Due to the small number of interviews conducted in total (seven), and their in-depth nature, they were analysed by hand. Whilst the transcribed interviews equalled a large amount of paper, there was a smaller volume of text to analyse and analysing it by hand allowed for a much closer reading of the text. Also, as the researcher who conducted the interviews, going through the transcripts by hand allowed for the additional inclusion of notes made during the interview (for example, gestures made) and as such adding to the richness of the data. Whilst the criticism could be made that perhaps there should be consistency in coding techniques, as the same individual did the coding for all data collection methods, it is hoped that this at least is consistency enough, and that the variety of coding options utilised has only strengthened the final results.

Media analysis

The second strand in this data collection process is that of an analysis of newspaper articles referencing ‘male breast cancer’. Newspapers were considered as appropriate for a discourse analytical approach, as they would enable the key research theme to be addressed, that of how do men experience being a breast cancer patient, and how this is to be understood. Discourse analysis is a route to studying meanings in text, and the use of newspaper articles provides a large amount of data from which to research this. In terms of the research question, men’s experiences of having breast

cancer would be reported in the media, as well as the huge amount of publicity attracted by breast cancer charities and organisations and events. Whilst stories may be concerning an individual man, these individuals are part of wider social worlds and it is these which enable an understanding of men's experiences of breast cancer to be understood.

Forum analysis

An internet forum is a site for discussions online, where individuals can engage with others in the form of posting messages. They are asynchronous interactions, as individuals can join in and leave whenever is convenient for them, unlike synchronous interactions (such as a chat group) (Eun-Ok and Wonshik, 2006). They also differ from chat groups as the messages are temporarily archived automatically, whereas in a chat group the conversation would have to be saved manually. Also, depending on the forum and the level of access to it an individual has, a posted message may need to be approved by a moderator before it is made visible to other users. The internet enables researchers to collect data from across the world, without the costs associated with traditional approaches to qualitative research (Joinson, 2005). Forums are a specific social world, and it is this which makes them appropriate for this research. The focus on how men experience being a breast cancer patient, and the mechanisms involved in this, can be seen through the examination of an enabler of this social world. The international accessibility of these forums means even if men are geographically restricted in accessing a breast cancer community, the internet provides them with an alternative entry.

A forum may contain a number of sub-forums branching off from the main area, and each of these may contain within it several topics and conversations, known as threads. Each thread can be replied to by any number of individuals who wish to do so. Whilst it may vary from forum to forum, users may have to register with the forum and then log in to the site in order to post messages. However, most forums do not require people to register/log in just to read messages which have already been published.

Many charities provide forums on their websites, in which members of the public can post comments, questions, or answers to other queries, thus creating social networks and an online environment. The use of collecting data electronically means people can communicate and share experiences and opinions without the need to travel. Online forums also provide a space in which people can talk about sensitive issues, especially as the need for registration and use of a password can help to ensure the confidentiality of the data (Eun-Ok and Wonshik, 2006).

The relevant threads (those on forums specifically for men with breast cancer) were copied and pasted into a Word document, with the URL at the top of the page for identification purposes. These were then printed off and analysed by hand. Being able to print the threads meant nothing was lost during a transcription process. Keeping the aims and objectives in mind, an initial reading of the threads occurred, highlighting recurring themes and areas of interest. A second, more in-depth reading allowed for these themes to be developed, in terms of how men experience being breast cancer patients, and also for these threads and themes to be considered in relation to one another.

NVivo

With such a large volume of data produced from the newspaper articles, it was decided to use NVivo as a coding tool. NVivo is a computer software package designed to support the categorisation and subsequent analysis of qualitative research. Documents are imported into the programme, and then analysed using different ways of visualising the data. Key points within documents can be highlighted, and the use of nodes means all the information on a particular theme can be grouped together. Other tools include the use of annotations to track ideas, and the use of modelling to visualise emerging links.

As both the discourse and context needed to be analysed for this research, this could have been problematic as language would be taken out of its original context. However, through the use of NVivo, a coded section can be placed in a specific node but the researcher can still find its original

location. Such an ability to locate coding may enable ‘competent researchers to do more rigorous, consistent, and thorough analysis than they otherwise might’ (Weitzman, 2000: 817). Similarly, by creating such a pathway within the programme, this has the potential to increase the trustworthiness of analysis and conclusions, as the researcher is able to show how these conclusions were reached, via these pathways. Such a process fits the requirements of a discourse analysis approach, which desires an orderly coding process and ‘avoids the condensation and decontextualization [sic] of meanings which is implicit in...quantitative versions of coding’ (Jensen, 2002: 248).

As the research process was begun with pre-defined categories, related to the aims and objectives of the study, therefore there is potentially the possibility that something within the data was overlooked, which perhaps may not have been had the research categories not already been defined. However, it is hoped that the combination of research methods used means that there will not have been a detrimental effect on the validity of the analysis due to any information that could have been overlooked.

A criticism of NVivo is that it could ‘enforce analytic strategies that go against the methodological and theoretical orientations qualitative researchers see as the hallmark of their work’ (Kelle, 2004: 478) and as such the researcher could potentially become alienated from their data. However, with regards to this research, it was not felt that such alienation would be a problem; as the focus is on language, metaphors, and meanings, this in itself requires a deep reading in order to code examples and therefore the use of NVivo, and having to distinguish examples, may actually enhance an understanding of the data.

Triangulation

Triangulation refers to the use of more than one method, or form of data collection (although it does not have to be limited to three) in order to investigate the same social phenomena (Taylor, 2001). This triangulation can check and/or extend the integrity of knowledge drawn from the data. There are arguments against its suitability: for example, on epistemological

ground, methods can be specific in terms of the data they yield, and so there is the risk that the evidence they generate is going to be discordant when combined with that obtained from other methods (Ritchie, 2003). However, a counter-argument to this position is that the value of triangulation is found within its ability to extend understanding, in terms of adding both breadth and depth to what is known about a social issue. As such, triangulation is able to provide a more thorough picture of the area being researched, but admittedly not one which can be said to be more certain. This research study had the aims and objectives of developing a deeper understanding of what it means to be a man diagnosed with breast cancer, and how charities incorporate these men into their work. As such, an approach which used a triangulation of methods is appropriate, as it lends itself to exploration. The discourse analysis approach has less emphasis on talk which is naturally occurring, meaning interviews and newspaper are a suitable target for analysis (Bryman, 2004), indicating that the methods are complementary. The three research methods focused on broadening what is already known in these areas, rather than searching for an overall truth: therefore, it can be argued that the arguments they yield are concordant with one another, because when combined they are able to take understanding further than previously.

Reflexivity

‘Reflexivity is a qualitative research strategy that addresses our subjectivity as researchers related to the people and events that we encounter in the field, and is an especially important consideration in the post interview period’ (Olliffe and Mróz, 2005: 259). Due to the nature of this research, and its focus on illness and gender, reflexivity is something that has to be considered throughout the data collection process, and also in terms of analysis.

One aspect that had not been considered as such before the process of data collection had begun was the need to debrief. This research study produced a number of emotive situations, due to its illness of focus. Whilst of course this research has always had such a focus, it shifted from being something read about to something with which I was becoming involved. Although I

tried to keep myself removed somewhat during the interviews, conducting these interviews with men who had all been diagnosed with a serious illness did have an emotional impact on myself, and as Oliffe and Mróz argue, '[I]t is integral for interviewers to recognize their own limits in order to sustain the demands of effectively interviewing men about health and illness issues' (2005: 259). It was hoped that by taking the opportunities to talk through my experiences with other researchers, and to spread out the interviews with men over a number of weeks, that such an emotional consequence of the data collection has not clouded the subsequent analysis.

It is quite possible that the sex of both the researcher and the participant may affect the dynamic within an qualitative interview (Oliffe and Mróz, 2005). Whilst of course there is no way to measure the extent to which this is true, it is possible that there was a tangible effect. Gender is one of the characteristics of humans which can contribute significantly to how we see the world (Oliver, 2003) and it is arguable that differences in gender may mean that researcher and participant could find it difficult to relate to one another.

At the stage of recruiting men with breast cancer to be interviewed, another man made contact, but when a reply was sent suggesting possible dates and times for interview, no response was received. A few weeks passed, and it was presumed this man no longer wished to participate. However, a reply was later received, explaining how he had been informed his breast cancer was terminal: he had been given around four months to live. As such, he did not feel he could participate in this research, and apologised profusely. A response was sent, thanking him for being willing originally, and wishing him and his family well. From a reflexive point of view, this was an emotional moment. Whilst this research project has always been about cancer, and of course it is known how devastating cancer and its treatment can be, this was the first time that death (or at least the closeness of death) had been experienced. The research moved at this moment from being abstract, to something more tangible. The respondents no longer seemed strangers who had kindly answered a call for participants, and instead had become individuals with a story to tell which went beyond the scope of this research project. Breast cancer, drug treatments, chemotherapy, these ceased to become something being read about for a doctoral thesis, or a

story covered in a magazines - instead they began to have another meaning, one which motivated this research project to ensure that the end result could do justice to the stories these men were willing and eager to share.

Ethics

This study was granted full ethical approval by the University's ethics board and at all times followed the ethical guidelines established by the British Sociological Association. The research participants involved all signed, or verbally agreed to (an agreement which was recorded), a participant consent sheet which outlined factors such as their right to withdraw at any point, how the data would be stored, and how all information would be kept as confidential and anonymous – pseudonyms are used throughout. All respondents agreed to the interview being recorded. Consent was freely given and was of an informed nature: all respondents had the opportunity to read the participant information sheet in advance which outlined the aims and objectives of the research, and the areas which would be covered in the interview. Respondents were also given the opportunity to ask questions. It was hoped that such precautions would ensure that the research relationship between the interviewer and the respondent would be one based on trust and integrity. This is further addressed in the section on reflexivity and interviewing men. The BSA statement of ethical practice posits that 'research relationships are frequently characterised by disparities of power and status' – hopefully by engaging in the good practice guidelines outlined here, the relationships entered into with respondents for this research have been more equal in status and power, in ways which have been mutually beneficial to all involved.

The use of the term 'participant' for those people involved in the research process implies that the research is being carried out in conjunction with them, and as such they do not necessarily occupy a passive role: they are fully involved in the research process (Oliver, 2003). The staff members interviewed for this research were accessed through a gatekeeper at a national breast cancer charity. This gatekeeper, also a member of staff, agreed and consented to the research in principal and then forwarded information to employees who may be in a position to participate. Contact

was then made with the researcher, and informed consent was provided by these employees also. Gatekeepers are concerned with how the research could potentially impact upon the organisation, and as such the researcher has an obligation to ensure that the research is not allowed to have an adverse effect (Oliver, 2003).

Considering involvement with organisations, participants may work within a hierarchical structure and so may 'need reassuring about the parameters of issues on which their organisation would approve of their commenting' (Oliver, 2003: 29). My gatekeeper approved the research, having seen a brief interview guide and did not necessarily know who had agreed to participate, so hopefully staff members who were interviewed were not concerned about being able to speak freely.

Considering the interviews with the men who had received a breast cancer diagnosis, it was of paramount importance that the psychological well-being of the men was not adversely affected by participating in these interviews. Before the interview was arranged, all men interested in participating were given the participant information which outlined the exploratory aims and nature of the research. This meant that all participants were aware of the nature of the questions being asked before they gave their consent to be interviewed. Whilst it may not be practical for people to know everything the researcher knows, in terms of informed consent, so this was interpreted as all the information a 'participant might conceivably need in order to make a decision about whether or not to participate' (Oliver, 2003: 28). For example, did not know about the specific charities in the forum analysis, just knew vaguely about the other data collection strands, but did know a lot about the interview section as that was the bit that could impact upon them the most. The men were also presented with contact details for support groups should they wish for them. The gatekeeper of the charity insisted that such information be available for participants, and I chose only to have information freely available on the internet so that I was not seen to be promoting certain groups over others. It is hoped that because the men knew the purpose and rough interview guide beforehand, then they were able to mentally prepare themselves for the interview and as such perhaps this reduced potential impact as they were arguably more aware as to how the interview process could affect them.

My research study did not offer any financial incentive to participate – whilst the offer was made for travel costs to be reimbursed, all the men were interviewed either in their homes or by phone, meaning no costs were incurred to them. The lack of financial incentive I do not think has detracted from the legitimization of the discussion about their experiences. By volunteering for this study, rather than being recruited (as such), this I think legitimates their experience and means the man himself is aware of the actuality of his position. All the men acknowledged how few men are diagnosed yearly with breast cancer and as such, volunteering for a study into men and breast cancer reflects their awareness that in terms of this research study they most definitely hold a legitimate position, as there are so few of them and also as it is hard to recruit participants generally. So being a minority in a minority means they are much appreciated. It was never going to be the case that this study would have too many men volunteering, and this is apparent, it may have been clear to all men volunteering that there was no chance of them being turned away and rejected. All men were welcomed into the study and this could further have legitimated their position within the research.

Research using the internet may encounter additional ethical considerations, which need to be addressed separately. Regarding accessing newspaper articles, as they were found through a subscription database, and had already been in the public domain, it is doubtful that such research could have a detrimental impact. Ethics with the forum analysis: the forums used for this project were all publically accessible. Whilst an individual has to register in order to post comments, this procedure is not usually required just to read what has already been submitted. All the comments used in the analysis are publically available – whilst there is an argument that the authors of these comments have not had the opportunity to consent to their comments being used in social research, they must have been aware, through registering with the forum in the first place, that their comments would be public and accessible to all. As such, there is an argument that by publishing their comments, they are agreeing to them having no control over who reads them. Whilst this is clearly not the same as giving informed consent to a study, using these forum comments in the way this research project has arguably has not had a negative impact on the authors. All names have been

changed. Due to their nature, forum usernames are often anonymous (such as, for example, Sarah51 or CountryGirl) and as such it would be very difficult to match posts to original authors, even if such data were available.

Conclusion

This chapter has explored the three main data collection methods, namely that of the media analysis of newspaper articles; the analysis of internet support forums; and interviews with men who have received a breast cancer diagnosis, as well as staff members at a national breast cancer charity. These have been explored from a viewpoint of using discourse analysis as the overarching research strategy. As has been discussed, there are different approaches to the use of discourse analysis, and this research study has opted for the utilisation of a blend of the common approaches in order to best research and explore the complexities surrounding men diagnosed with breast cancer. Discourse analysis focuses on how language is used in a particular place and time, how knowledge is produced within a discourse, and how discourses are constructed and altered. Because discourse analysis allows for language and meaning to be explored in terms of how they are recorded and reported, the use of discourse analysis within this research study allowed for men's experiences of being breast cancer patients to be expressed in their own way, and provided the means by which these experiences of theirs are to be understood.

The three data sets of interviews, media analysis and forums analysis relate directly to the research aim of exploring how men experience being a breast cancer patient. Interviews allowed the men to give their own accounts of their experiences, providing the opportunity to understand meanings from their point of view. Searching for newspaper articles allowed the key themes to be addressed, as men's experiences would be reported. Whilst stories may be about one man, people are part of wider social worlds and it is these which enable an understanding of men's experiences of breast cancer to be understood. The forum analysis allowed for data to come from all over the world, if men were unable to access a support group locally, the internet provides them with an alternative. Forums allow people to

communicate (anonymously should they wish) and share experiences, providing information as to what it means to be a man with breast cancer.

Whilst criticisms may be levelled at the study, for example the relatively few number of interviews, these have been discussed in order to show how they have been considered most appropriate for this study. The use of triangulation in terms of data collection strategies will ensure that breadth and depth are obtained in terms of knowledge of the complex issues, although a position of overall truth is unlikely to be obtained. However, this is appropriate to the aims of discourse analysis, which is the study of language as it is being used in a particular social context. As such, the combinations of the strategies utilised will hopefully yield the most accurate data possible from this study. Finally, this chapter has addressed the reflexive process undergone throughout the data collection and analysis, focusing specifically on the role and attributes of the participants and researcher, and potential consequences of conducting research in the areas of masculinity and health.

Chapter Four

Hegemonic masculinity, and the challenge of breast cancer

Introduction

Bury (1982, 2011) argued that for someone who has a chronic illness, everyday life is disturbed. How the individual had previously seen their day to day life, and how they thought their life might be in the future, is altered following diagnosis of a chronic illness, given the potential impact of such a condition. Alongside this comes the need to recognise pain, and perhaps the possibility of death, which are usually seen as happening only to others. People with a chronic illness need to consider their biography as well as seeing what resources (such as medical and financial) are available to them. Chronic illness can undermine the structures people use to construct their narratives of self (Reeve et al, 2010) and so plans which had been made in the past, pre-diagnosis, may no longer be feasible, practical, or even desirable post-diagnosis. Diagnosis of a chronic illness may undermine how people had previously seen themselves and others, meaning these structures need addressing in order for the individual to move forward.

However, caught up with this idea of individuals being required to restructure their identity following diagnosis, is the assumption that such a restructuring of identity is indeed possible. Some illnesses may be more straightforward than others, in terms of how they can be incorporated into the biographies of the individual and their family and friends, but others may be more complex. This is especially true of rare diseases: breast cancer itself is not a rare disease, and there is a plethora of information available for both individuals diagnosed with the disease, and for their friends and family. However, breast cancer in men is rare, with a lack of appropriate information. The work of Bury's biographical disruption implies that people are able to restructure their lives following diagnosis of a chronic illness, and whilst this may not be straightforward, and may be a lengthy process, it is still achievable. However, there are not enough analytical tools provided to understand how breast cancer affects the shaping of a man's identity following diagnosis. Whether it is through the dearth of

information targeted at men, the perceptions of others, or wider ideas of masculinity, a breast cancer diagnosis for a man can be seen as a threat to maintaining an identity congruent with ideas of Western hegemonic masculinity. The ideas surrounding biographical disruption are not able to adequately explore the consequences of a breast cancer diagnosis for a man.

This highlights the relevance of applying Park's theory of the marginal man to the experiences of men diagnosed with breast cancer. Their position of being spatially within a group, and yet not rooted within its fundamental systems, allows for them to be privileged in terms of widening understanding of what it means to be a man with breast cancer, but also increasing awareness of the larger social world, and the wider breast cancer community. This chapter uses data from the three datasets to explore the experiences of men in their diagnosis and treatment, how they started their journey into joining the breast cancer community. It engages with ideas of masculinity, how masculinity and femininity are viewed as constructs both before and after diagnosis, and how breast cancer can alter people's perceptions of others. Engagement with the medical profession is a necessary element of being diagnosed with breast cancer, although following diagnosis there is a myriad of ways in which men (and women) can shape their involvement and engagement. It is the experiences of diagnosis and treatment with which this chapter starts.

The experiences of men in diagnosis and treatment

Although their specific experiences may differ significantly, what all men diagnosed with breast cancer share is being told the specifics of their illness, and what medically the next part of their journey might be. In general, men often took longer to go and see a doctor, due to not realising there might be a problem. For those who did see a doctor quickly, this knowledge came from media campaigns, and often the change was only noticed because of these campaigns. In medical settings, men were usually assumed to be present as supporters of patients, not as patients themselves. The lack of information about breast cancer in men means men are not able to make fully informed decisions in the way that women diagnosed with breast cancer are. It is the individual experiences and situations of these men

which shape whether and how a breast cancer diagnosis can challenge hegemonic masculinity. In order to examine this further, it is necessary to start with how the men were originally diagnosed with breast cancer.

The interviews with men diagnosed with breast cancer began with asking them when they first suspected something was not right. This question was asked in order to ease the men into the interview, and to establish how their experience with breast cancer started. From the responses, Michael's original concern about a lump, for example, was not associated with cancer, as he had experienced fatty lumps. He found his lump in July one year, but did not see a doctor until the October. Michael delayed going to the doctor, partly because he thought he knew what it was. This relative lack of concern and delay reflects an element of hegemonic masculinity: an ideal of hegemonic masculinity is being strong and not seeking help or overly worrying, and this is what Michael was enacting. Equally for this man, given his medical history, he did not see lumps as threatening and so was not further motivated to see a doctor quickly. A hospital appointment was made for December and then in January for a follow-up. Following a scan and mammogram Michael was asked to go to the breast care clinic at another hospital for a biopsy. Regarding the staff who did his biopsy:

‘they’re looking, obviously they must have known, I am so stupid, I didn’t know, simple as.’ (Michael, 07/05/11, p. 3)

He felt ‘stupid’ as despite him being in the breast care clinic, he had not yet considered that his breast lump could be cancerous. In how he viewed his situation there is what can be seen as a gender blind spot. His awareness and understanding of breast cancer before his diagnosis meant that he viewed breast cancer as only a disease of women: even when he found himself in a breast care clinic, this blind spot meant he did not consider his diagnosis could be breast cancer. With hindsight, he felt ‘stupid’ about this as it now appears to be obvious.

Michael's original follow up appointment in January was rearranged for a closer date. Even when he was in the breast care clinic

‘the only guys that were there were like husbands and boyfriends and then they called my turn and just er go in and they all look at me what’s he going in there for, it’s a breast clinic! Me still being stupid, [I] don’t know.’ (Michael, 07/05/11, p. 3)

It is assumed by both Michael and the other men and women in the clinic that the women are the patients, and the men are only there in a supportive capacity. This assumption stems from a viewpoint of hegemonic masculinity, in which men are not seen as being patients, especially in a location which is so strongly associated with women, and that as such the men can only be there in a non-patient role. An alternative scenario does not fit with this view of hegemonic masculinity, and so is not given consideration. When Michael’s name is called, and it transpires to everyone that it is he who is the patient, he is already being viewed in a different manner to how he had been previously. In terms of ‘doing’ gender, Michael’s current situation of being a patient in a breast clinic does not fit with how a masculine identity is portrayed and accepted by others. Whereas before he was seen as occupying a peripheral position in this situation, his new identification as a recipient of medical care in a breast clinic means that the perceptions people held of him a moment ago have now been altered. This is a threat to how he fits in with ideals of hegemonic masculinity, and also how he has now been marginalised. Rather than be a part of the large group of women needing medical treatment, or the men who support them, he is now positioned within a much smaller group of men requiring this medical treatment. It is the positioning of him in this marginal position which threatens how he portrays his masculinity.

Leading on from this declared feeling of stupidity, when Michael was asked if he really had not considered cancer as a possible outcome of these medical investigations, he replied:

‘absolutely, I’m absolutely, cos I never ever heard of [men getting breast cancer] you know.’ (Michael, 07/05/11, p. 3)

When he was eventually given his breast cancer diagnosis:

‘I just went [exhales loudly] that’s that, men don’t get breast cancer, oh yes they do and you’ve got it. So, all you hear is the C word, you hear cancer. Cancer. And they’re rabbiting on, telling me what’s going to happen and I’m not, I, just, I’ve got cancer.’ (Michael, 07/05/11, p. 3)

Michael’s enactment of exhaling loudly, and the accompanying dropping of his shoulders, reflects the moment at which his world changed. His previous view of himself as a relatively healthy man, with certain plans for the future, was in that moment changed as he needed to begin to incorporate this diagnosis into his identity. This reflects a clear sense of biographical disruption, as not only has he learned something new in terms of his health, he has learned that it is not only women who can have breast cancer. Here, illness is impacting on how he perceives his identity: even if he had considered the general possibility of becoming ill in the future, the diagnosis now is unexpected, especially considering what the diagnosis is of. Cancer is a serious diagnosis, which will influence how he comes to see himself as a cancer patient, but this inclusion of a cancer diagnosis is made harder as the specific type of cancer is previously seen as being impossible for him to have. His evolved identity has to now include this ‘impossibility’. Whilst all medical diagnoses are likely to disrupt a patient’s biography to some extent, this is even more true when that diagnosis is one which previously was understood as impossible. This shows the applicability of Park’s marginal man theory as men in this position lack the information about breast cancer in order to re-establish their biographies and as such are placed in a marginalised position.

However, in comparison with Michael, both the other men interviewed were aware that their lump could potentially be breast cancer. As Paul explains,

‘I was seeing something on tv, erm, about men with breast cancer [...] I’d never known before I saw it that men got breast cancer and whilst I was having a bath, I was having a feel. And on the right side I felt just a very, very small lump.’ (Paul, 12/5/11, p.1)

He went to his GP, who referred him for an ultrasound and biopsy, the results of which showed:

‘it’s cancer [...] you don’t believe it, it’s almost surreal.’ (Paul, 12/05/11, p.2)

The idea of situations being bizarre, defined as surreal, implies that they are not real and are almost not to be believed. Whilst Paul had learned from the television programme that men could be diagnosed with breast cancer, he had not seen himself as being in that position, and as such he found the reality surreal, as he had not incorporated this possibility into his biography. He was being told by a doctor that he had breast cancer, and yet he was not able to see this as real.

In Richard’s case, he had:

‘read something within the previous three weeks [from finding a lump] in er one of the dailies some young chap younger than me who’d got it and got it checked out’. (Richard, 20/06/11 p.2)

Following a biopsy, Richard received a diagnosis of breast cancer. Arguably, this awareness of male breast cancer was what prompted both men to visit their doctor as soon as possible. Richard says that:

‘it would never have occurred to me to check my breasts particularly or anything like that.’ (Richard, 20/06/11 p. 8)

It was the television programme he watched which prompted him to have a feel. Richard did not realise that men could have the disease. Michael said that he felt:

‘absolutely stupid now, because you know, I’ve gone through the mammogram and I’ve gone through the others [tests] and I said [to his breast cancer nurse] I should have twigged, I said but I’ve never ever never *ever* heard of men getting breast cancer.’ (Michael, 07/05/11, p.4)

Michael was adamant that he had never heard of the disease in men before, and not only did he not know about it, it was something that he just would

not have considered possible, had it been suggested to him. If Michael had been aware of breast cancer in men beforehand, this may have encouraged him to have visited his GP sooner. It is this issue of awareness, and the associated issue of increasing it, about which he is now so passionate. Rather than ignoring physical symptoms, or assuming that they are nothing serious, men need to engage with their health in order to be aware of possible diseases so they can be proactive in terms of seeking help. Increased awareness of diseases in general can be linked with an understanding of physical changes, all of which could encourage help-seeking.

The idea of ‘doing’ gender as discussed previously shows how gender is seen as an accomplishment: as part of this accomplishment, and for other people to see the individual as their desired gender, men need to follow certain accepted ideals. In this instance, Michael has maintained a strong masculine ideal by not being overly concerned about his health. To appear to do otherwise, and seek advice about a physical change which may not even be a symptom, is to undermine the hegemonic masculinity which emphasises health and strength. Yet on the other hand, it could reinforce a strong masculine identity, as by becoming more knowledgeable and aware of health issues, men could find themselves in a stronger position to take control over their health and wellbeing. This in turn could mean they maintain a position from which they can continue as providers for, and supporters of, their family and friends.

This issue of general lack of awareness was also present in the forums data. A man posted on a British forum and explained he:

‘didn’t know men could get a breast lump’ (*david1940*, British2, 08/03/2011)

and that he has hospital tests booked following a visit to his GP. He admits that he is unsure as to where he should start. His lack of previous knowledge of breast cancer in men has meant that he has been so far unable to incorporate this into his identity. By not knowing where to begin, he is showing how unlikely his situation is. Although there is a vast amount of information on breast cancer accessible with very little research, not having

a starting point means men are at a further disadvantage in terms of being able to adapt to this new aspect to their identity.

The first response to this post said:

‘there are many of us ladies on this forum who can give advice and comfort through first-hand experience and it won’t be long before other people reply to your posting’ (*mirror*, British2, 08/03/11)

The use of the phrase ‘Us ladies’ straight away separates the two genders into a group which can be seen as cohesive, the ‘ladies’, and a second group which is only formed in a loose way. It is not clear whether she means that it will not be long before men eventually come along and post, or whether other women will reply in due course. The next reply is from a man who has breast cancer, and who is launching an awareness campaign because so little is known about this ‘‘lady’s [sic] disease’ (*RunningDrums*, British2, 08/03/11). Acknowledgment is made here of the majority group, and how breast cancer is overall considered a disease for women. What is shown here is the existence of a gender identity and an illness identity, and how one may be seen as dominating another, when actually it would be more beneficial to be the other. This response of ‘us ladies’ is positioning individuals into two categories, men and women, with this categorisation being strong in how people are seen by others. The shared identity feature of both people having received a breast cancer diagnosis is seen as secondary to gender identity, and that perhaps the (male) original poster needs to wait until other men reply to his questions, as their shared gender identity will be of benefit to him.

In terms of challenging a sense of hegemonic masculinity, this quote reflects men diagnosed with breast cancer having to learn more about an illness which is usually acceptably associated with women, and so these men are no longer being seen as being in control and knowledgeable. Breast cancer in women is relatively well-known, in terms of an illness and its public awareness. Men diagnosed with breast cancer have to learn to view the illness in a new light, and how it affects them now as individuals. As has been shown, the public generally has little knowledge about breast cancer in men, and so male patients diagnosed begin from a starting point of not

having much prior information themselves compounded by there being little information available. Hegemonic masculinity positions men as being knowledgeable, not necessarily just about health, but in terms of maintaining a strong position and being at an advantage. This is threatened by a breast cancer diagnosis as these men do not have the knowledge they need, both in terms of not being in a position to do their own research, and also there being a dearth of knowledge about breast cancer in men in general. Likewise, hegemonic masculinity emphasises the control men have over their lives and their identities which again is threatened by breast cancer. The lack of medical information about breast cancer in men may mean male patients are limited in their therapy options, due to there being a lack of information about how effective certain treatments are for men, when compared with the data available for breast cancer in women. As such, men are not able to make the variety of decisions regarding their treatment options that women can. Men also do not have control over how their breast cancer diagnosis may be seen by others, given its rarity, and men may be viewed as being in a vulnerable position, a position which does not embody hegemonic masculinity. Potentially, this could allow for both women and men embodying a different form of masculinity other than hegemonic to gain a social advantage and pose a threat to the dominant hegemonic masculinity within this context.

From these posts there is a sense of needing to wait for someone with the relevant experiences to come along, and men are not in control of this. On the thread, a link is posted to the website's section on breast cancer in men and the poster acknowledges that it 'gets a bit daunting, but you are in good company on here'. Previous posts may have marked out the majority from the minority group, but this message brings the two groups together in a shared experience, although this shared experience may often be overshadowed by the ideas of the relevance of an individual's gender identity.

Traditionally, women have been assisting men with their health and well-being and arguably this could be a convention of hegemonic masculinity, with both men and women accepting this positioning. Whilst this may be relevant for many illnesses, the rarity and unexpectedness of breast cancer for a man can negatively impact upon ideals of hegemonic masculinity as

men are having to ask for help in a situation where no-one expected them to be.

Ideals of masculinity

Masculinity in a woman's world?

The idea of gender identity and its associated attributes are reflected throughout the datasets in terms of how breast cancer is perceived and also reported. It is true that breast cancer is a disease which is diagnosed in significantly more women than men, and also that it is through the actions of women in the past that women today are so aware of the risks of breast cancer, as shown in this quote from a newspaper:

‘The fact that the fight against breast cancer has become something that women own is in large part a function of the fact that they have every right to own it. Just not entirely’ (*Esquire* (USA) 06/01/00).

What this quote highlights, is that yes, women are entitled to a key role in the breast cancer discussions and campaigns, because they have done so much to bring it to where it is today. However, there are a number of men diagnosed each year and they need to be included, in what needs to be a balancing act, between acknowledging and respecting what has been done in the past, and considering how this can be built on in the future, in order to help and support all individuals diagnosed with the illness.

The actions of women over the past few decades have firmly entrenched breast cancer as being seen as a disease affecting women. This is shown in one thread from the US which is started by a woman who writes that her husband has just been diagnosed with breast cancer and:

‘he is “ashamed because he has a “woman’s disease”. I’m having a hard time reconciling his embarrassment with telling the truth. He wants to tell people he has a “tumor [sic] in his chest”. I think he should just say right up front what he has, but [I] will respect his wishes.’ (*SarahOH*, USA, 01/05/11)

The use of 'ashamed' is relevant as it shows how the man feels he will be seen by others. To have shame is to try to prevent something from offending other people, as this shameful experience could be seen as violating social or cultural norms. This man is ashamed of his diagnosis as he feels that he has broken a norm, by having a woman's disease, and as such is fearful that he will be viewed negatively by others. He feels unable to inform people of his diagnosis as he is concerned that they too will view him in such a way, impacting negatively on how he perceives his masculinity. This again displays the possible confusions between an individual's gender identity, and their illness identity. This woman's husband now has to identify as a person with breast cancer, but he struggles to see himself as a man with breast cancer, and instead views himself as a man with a 'woman's disease'.

The original poster asks how other men told people they had breast cancer, and a succinct reply comes from a lady who says

'I think all of us don't like to say we have breast cancer, even if we are women, so I understand your husband's feelings.' (*43vintage*, USA, 01/05/11)

This is a fundamental point, in that breast cancer is a hard diagnosis for all people to receive and it should not necessarily be assumed that it would be harder for men, given their additional difficulty of having to come to terms with perceived threats to their identity as men. Whilst women are the ones usually diagnosed with breast cancer, this positioning within the majority group does in no way mean that this illness is easy to come to terms with, or that women are happy for other people to be aware of the diagnosis.

One woman asks,

'Does he think he's less of a man because of the type of cancer he has? I hope not, and if so, I hope he gets over that soon.' (*jane246*, USA, 01/05/11)

In terms of masculinity, there is a risk that a breast cancer diagnosis will mean that a man could be seen as less of a man in the eyes of some individuals, given that he has what is considered to be a women's disease. The fact that this is acknowledged here implies this is a real possibility. From the way the quote is phrased, this feeling of being less of a man is something that all men diagnosed with breast cancer *will* face, when this is not necessarily going to be true. This opinion, that men will feel less of a man following a breast cancer diagnosis, implies breast cancer is automatically to be viewed as a threat to masculinity, that there is something inherent within the disease that causes this to be the case. This is not true, as it is not the illness itself which can be seen as a threat to masculinity, but rather people's perceptions of breast cancer, and how they react to those who have been diagnosed with it. Therefore it is not the biological consequences of the illness which can be seen as threatening towards masculinity, but rather the consequences of people's actions, and how those diagnosed with breast cancer perceive themselves, and how they are perceived by others.

There are a few more messages of support and then the same woman of the previous quote suggests that,

'men are commonly bald, and men don't have big boobs, which aren't generally as much sensual organs like women's are. Not trying to minimize his loss, but it may be easier for him to deal with than it would be for a woman.' (*jane26*, USA, 01/05/11)

There is an assumption contained within this quote that men are less likely to be affected by a breast cancer diagnosis and subsequent treatment, as their treatment is less visibly obvious than similar treatment for a woman. A common side effect of chemotherapy, hair loss, could be assumed to be common balding in men, and in day to day life it would be hard to identify men who had undergone a mastectomy. Breasts do not have the same sexual connotations for men as they do for women, all of which build to the assumption given here that a breast cancer diagnosis will affect a men less than a woman. Here, the marginality of men is reflected because they are unable to fully be integrated into the breast cancer community as their loss is less significant than the loss of others, a loss which cannot be measured.

It cannot be measured, as there is not a base from which to start: for women, cultural and social norms surrounding their breasts exist, and so it is easier for them to be integrated into the breast cancer community as there is previous knowledge about their potential experiences. Both men and women, however, may not previously have considered men's breasts as having any significance, or even considering them as having breasts at all. Men who then find themselves diagnosed with breast cancer, and face losing their breasts, may be unable to establish the significance of their loss, to themselves or others, as there is not this prior general knowledge and awareness available. Continuing along the assumption that men are less affected, they can be seen as coping well with the illness, perhaps better than women, an attribute which helps strengthen their sense of being 'manly'. If men are seen as being stoic, this too could strengthen ideals of masculinity as these patients are engaging in fewer public contexts, and not bringing attention upon themselves. Whilst being diagnosed with a 'feminine' illness may temporarily impact upon a man's perception of himself, this may change dependent on how this man engages with the wider breast cancer community.

A man replies to this thread saying:

'I'm secure enough as a man that it did not bother me to tell people [...] your husband would be doing a service to other men to tell people that he has breast cancer.' (*Mike55*, USA, 02/05/11)

This quote that he is 'secure as a man' raises the question as to what he means by this notion of security. The use of 'secure' as an adjective means this man is fixed in his masculinity, and fastened strongly in such a way that he cannot become lost from this. He sees himself, and believes others see him, as a man, and he is fixed strongly to this in such a way that a breast cancer diagnosis is not going to loosen the security of his masculinity. He has the strength to speak up and out about his diagnosis. 'Secure' also suggests the individual is in control of his identity, but as has been shown through the work of Bury (1982) illness can disrupt one's identity. For this man, therefore, he is declaring himself to be secure both in terms of his masculinity, as well as secure with his identity pre-diagnosis, and how breast cancer has had less impact on how he sees himself. The implication

here, though, is that whilst this man is secure in his masculine identity, it may not be the same for other men, and weaknesses in how securely they are attached to their masculinity could hold them back from revealing their diagnosis as they do not want their security as men to be further undermined.

This man in the above quote is secure enough in his framework of masculinity that he does not feel this could be irreparably damaged if others were to know of his diagnosis. Active participation in health care, and making this public knowledge, may be viewed as feminine, but the continuing security of a sense of masculinity can be rooted in the strength traditionally associated with masculinity. Herein lies a paradox, in that whilst being active in terms of participating in health care can be deemed feminine behaviour, a strong sense of masculinity implies a strength, and the stronger this strength, the stronger the sense of masculinity. The behaviours attributed to femininity may, in a way, help support masculinity, if the man in question is firm and strong in his perceptions of himself, and how he believes himself to be perceived by others. A man projecting a strong sense of masculinity is perhaps less likely to find his identity questioned than a man who projects this sense less strongly.

In the previous quote, being ‘strong’ refers to being strong in terms of illness and facing adversity, two aspects faced with a breast cancer diagnosis. The second part of the sentence in the above post implies that men, being a minority group, have almost a duty and an obligation to be public about their diagnosis in order to increase awareness and as such encourage men to come forward. Whilst these men did not choose to become breast cancer patients, and so did not choose to become advocates for those men who are diagnosed with the disease, the fact that they are in this position means they are in an almost unique position to be able to help the other men who will be diagnosed after them. Being in a minority group immediately means that there are fewer people who understand their social positioning and viewpoint, and as such are in an almost unique position to be able to help the other men who will be diagnosed after them. Being in a minority group immediately means that there are fewer people who understand their social positioning and viewpoint, and as such they are the only ones who can act in such a way that other people may benefit. By this

man being secure in his sense of masculinity, and in turn his identity, and also in his view of how he is seen by others, this individual is able to do his duty in terms of helping others to be as secure as he is.

On the same thread as above, after a few more messages of support, the original poster writes

‘As great as this site is, it IS mostly dedicated to women’s breast cancer and finding appropriate forums is not that common.’
(*SarahOH*, USA, 03/05/11)

To which one woman replies:

‘I come on the male cancer site sometimes to remind the guys that breast cancer knows no sex and there are a lot of good topics and advise [sic] on the other, (female side). (*ab999*, USA, 15/06/11)

The assumption implicit here appears to be that many of the issues associated with breast cancer are the same for many patients, regardless of gender, and as such information and messages posted in other sections of the forum may be of relevance to men using this section. There also could be within this a second assumption in that a lot of breast cancer information for men is based solely on the appropriate information for women, and that no specific information is available. Therefore, in such circumstances the best option men have is to utilise the forums for women. This reflects on notions of identity as for men having to utilise forums for women entails them becoming more in touch with their feminine side. If information aimed solely at men is lacking, men need to engage with feminine aspects of their identity in order to be most receptive to the information available. Information on, for example, drug side effects may not be directly relevant to men but by viewing it from a feminine perspective, there may be elements that can be utilised. Until such specific information is available for men, which supports their masculine identity, women may need to encourage men to use ‘their’ (women’s) sections to ensure that men are accessing the support and knowledge which is available to them. Five months after starting this thread, the OP reports that her ‘husband is totally fine with saying he has breast cancer now. Not that he’s out there wearing

pink ribbons and such, but he isn't "ashamed" any more.' This husband has been able, to some extent, to access feminine aspects of his identity to help with a transition in becoming comfortable with publicly acknowledging his diagnosis. This reveals moral obligations to gender, in that a man participating in healthcare can still be seen as strong and masculine if he is resolute in how he sees himself, and also how he perceives others as seeing him. This above comment also indicates there are levels of involvement within breast cancer communities, enabling individuals to become involved to the extent with which they feel comfortable.

The final post on this thread is from a man who thinks:

'I may be unique in that I don't really give a rat's a\$\$ [sic] about what people think and I've been really open about my diagnosis.'
(*Brian_Ball*, USA, 15/03/12)

This quote is in contrast to the ones above, which have shown how men have had to work on their level of gender identity in order to properly engage with the wider breast cancer community. As he has been 'really open' about his diagnosis and has not given 'a rat's a\$\$' about what people think, he has not had to engage in identity work; his sense of identity has not been threatened by his diagnosis of breast cancer, rather he has 'done' gender and has found a way to incorporate this diagnosis into his identity. He has been secure in his masculine identity, and therefore breast cancer and subsequent conversations and events have not jeopardised this, they have managed to be included. However, the admission that he 'may be unique' in this does reflect the identity work performed by others: they have cared about how both they and others see themselves and as such have embarked upon identity work. This work is visible, as this forum user has enough understanding of it to feel that he is unique in his avoidance of it. The OP's husband has clearly gained a level of acceptance with his diagnosis, and as such is 'totally fine' with people knowing about it.

Even when men did feel able to tell others of their breast cancer diagnosis, there was the possibility that they simply would not be believed, as Mr Steele, a man diagnosed with breast cancer, discovered when he 'found that many people simply did not believe he was suffering from what is

commonly regarded as a women's ailment' (*The Scotsman*, 11/26/02). The use of the word 'ailment' here is of interest as it is one which usually refers to a milder and shorter-lasting illness condition. The use of it in this context either implies that the health concerns of women are less significant, or that breast cancer in men is perhaps less serious than it would be for a woman, an idea which has been expressed in other articles. Whilst articles have suggested that breast cancer affects men less than women, for patients this may be largely irrelevant: as Mr Rubenstein, another patient, succinctly summarises,

'I was too worried about having cancer to care too much about the fact that, usually, my illness only affects women' (*The Jewish Chronicle*, 06/19/09).

A diagnosis of breast cancer is a diagnosis of a serious illness, and arguably there are more important elements on which to focus rather than fret about the gender of the patient, or how the individual is now going to be viewed by others. By not dwelling on the fact that breast cancer could be seen as detrimental to masculinity, Mr Rubenstein is placing himself in a position from where he is able to concentrate on his health, rather than on how he may be seen by others.

Masculinity and the male body

Masculinity seen as something biological, that it is not something socially constructed in terms of health, is expressed by Mr Goldstein, a man diagnosed with breast cancer, who is quoted as saying:

'Men do not socialize diseases very well. One of our defective genes is the macho gene, and we very often fail to acknowledge that we can be a candidate for a disease, let alone a 'woman's disease'' (*The Toronto Star* (Canada) 08/09/02).

Here, breast cancer is defined as being a 'woman's disease', although the use of inverted commas within the text implies that this is not quite fact, and something thought by someone else. Breast cancer may be seen as a disease

for women, but a few people understand that it is not only for women. If a person researched breast cancer, they would learn that it can be diagnosed in men, yet as this is unlikely to be the first piece of information uncovered, many people lack this understanding. One element of masculinity raised here is the idea of being ‘macho’ and not concentrating on one’s health and wellbeing, and how this behaviour is commonly viewed as a biological trait found in a ‘defective gene’. This ‘macho gene’ means men do not see themselves as likely to be affected by disease, especially not a disease they would not even consider themselves as being able to affect them. Genes are a biological feature but it is the social construction of gender which has men not worrying about health matters. This ideal of hegemonic masculinity is seen as natural through the idea of a ‘macho gene’ when in fact it has been constructed and developed through the social behaviour of individuals and groups.

Such an attitude towards help-seeking may ‘have had serious consequences for overall levels of early male mortality’ with men needing to ‘react to what is going on in themselves’ if they are to avoid serious problems, argues Dr. Meryn (*The Globe and Mail* (Canada) 11/13/01). However, as argued by Mr Samuelson, who was diagnosed with breast cancer, men do not like to think of themselves as having breasts, instead having ‘pecs’. This can be seen as a way of further removing themselves from breast cancer, as they do not need to acknowledge a ‘female’ body part. In line with this:

‘Men don’t think about their breasts. They don’t even use the word. For them, it’s their chest, their pecs’ (*The Hamilton Spectator* (Canada) 04/12/03)

which also increases difficulty as men, who may find it unusual to talk about their body in an illness-related way, are now finding themselves in a position where they need to do so.

Similarly,

‘For many men, the idea of having an exam for breast cancer is embarrassing – even emasculating. When Richard Roundtree was told he had breast cancer “I felt he was questioning my manhood.”’

(The Boston Globe (USA) 08/06/02).

To be required to undergo a breast examination can be seen as ‘emasculating’ as for a man it involves his body being seen and touched in a way normally only done with women. The man is no longer seen solely as a man, but as someone who could have a breast disease. This moves how he is seen by himself and others further away from ideals of hegemonic masculinity as the focus is a part of his body that before had never been considered a threat. Masculinity is threatened as the individual is on a par with women, by having a breast disease, when usually a hegemonic masculine position is dominant and one which subordinates women and other groups of men. Another ideal of hegemonic masculinity is that of strength, especially physical strength, and to be diagnosed with a serious illness goes against this, especially given the associations of breast cancer as a ‘women’s disease’.

To receive a breast cancer diagnosis is threatening not just to health as a whole, but also to an individual’s sense of who they are, and how others see them:

‘As a male breast cancer patient of some 17 years, I must admit I get mildly annoyed when it is referred to exclusively as a disease of women, which is just about all the time. While breast cancer is obviously a bigger issue for women than men in global terms, it is just as big an issue for those males who contract the disease’ (*The Globe and Mail (Canada) 03/01/06*)

Whilst women are the majority group, they are not the only group, and it is understandable for men diagnosed with breast cancer to feel ‘annoyed’ when the disease is referred to as being exclusively for women. To move away from an idea of exclusivity, whilst still maintaining a focus on women, would enable men to feel more included, and would also provide knowledge and awareness to people of both sexes who may be affected in some way by the disease in the future.

A humorous approach is taken by Mr Crew who jokes “‘If I ever slipped and fell, I wouldn’t go tits up, because I only have one.’” (*The Globe and*

Mail (Canada) 11/13/01), but such an attitude cannot detract from the severity of the diagnosis. The use of humour here is used as a distancing tool, to move focus away from the severity of the illness. By using humour, and referring to his breast tissue as ‘tits’, focus moves to the joke, rather than the disease. The use of slang terminology also means he does not have to acknowledge that he has breast tissue (so closely associated with women) and therefore this is seen as less of a threat to his masculinity.

Mr Nathanson, who was diagnosed with breast cancer, believes that:

‘some men might be embarrassed saying they’ve got breast cancer. They might feel it was attacking their masculinity somehow. They shouldn’t. I knew if I was going to beat it I had to face up to it. Saying it matter-of-factly made it easier for people to accept. Everyone was incredibly supportive.’ (*The People*, 09/26/04).

Although breast cancer is associated with femininity, facing up to a diagnosis in the way outlined by the man in the previous quote reflects masculine ideals about strength and winning, and being open about the diagnosis is likely to mean that people are more accepting of it. A stoic attitude may also impact on how men present themselves to others, not wanting to complain about their mastectomy scars as they feel women will have more to endure from the same operation (*The Hamilton Spectator* (Canada) 04/12/03). This article later explores the suggestion that men do have a relationship with their breast, in a way women may do with theirs, although for men it is more about their general chest area than breast tissue in particular. Chest muscles can be associated with ideas of strength and feelings of masculinity, and therefore they may have a sexual function, as with women, but just in a different manner. As one medical professional said:

‘There is this idea that men aren’t disfigured [after a mastectomy], but they may feel quite injured. Men are proud of their chests. It’s that Tarzan thing.’ (*The Hamilton Spectator* (Canada) 04/12/03).

The reference to Tarzan (an early 20th century fictional character who is raised by apes, falls in love with an American lady, and later rejects life in

America in order to be an adventurer in Africa with his wife and child) invokes imagery of a strong (often topless) man, one who is at home in dangerous environments, who embraces adventures, and is able to protect his family. The implication here is that all men have a 'Tarzan thing' in which they are proud of their chests as a sign of their health, physicality, and masculinity. To threaten the appearance of their chests is to ultimately threaten how they see themselves, as breasts do have a role in male embodiment, just a different role from that in female embodiment, and also how they are to behave now that this area of their body has been damaged. Women's bodies post-mastectomy may be more visibly altered than that of a man's post-surgery, but there is a risk that men's chests could become concave, due to chest muscle being removed to ensure there is a healthy margin around the tumour on removal.

The idea that men ought to be 'macho' even with a breast cancer diagnosis is portrayed in a number of articles. One wife explained how her husband had surgery one Wednesday and was back at work the following Monday because "'He's a man'" (*The Gazette* (USA) 07/07/08) therefore implying that he was going to recover from his (serious) operation as quickly as possible and do his best to 'get on' with the situation as he did not wish to be viewed as someone who was taking longer than perhaps was necessary to recover, a view which could inflict damage on his masculine identity. An acknowledgement of the masculine ideal is made by Peter Criss, a member of the rock band KISS, who

'knows that many of his male fans are macho, so he is making the rounds to tell them even tough guys can suffer from a disease usually associated with women – breast cancer [and] he hopes his heavy metal credentials will help mitigate the stigma around breast cancer for men' (*Ottawa Citizen* (Canada) 10/22/09).

If a man who is viewed as a very masculine man, both in himself and his presentation, this may help to make breast cancer seem less threatening to men in terms of negatively impacting upon their notions of masculinity. A similarly strong epitome of masculinity is held by the Dreamboys, a male dance group, who assisted Mr Avery in launching his campaign to raise awareness of chest cancer (*Yorkshire Post*, 06/17/09). Whilst it may be

anatomically inaccurate, if it helps bring attention to the illness and the possibility of diagnosis, then this may impact positively on awareness campaigns. It may be especially beneficial for women, who are the target audience for the Dreamboys: if women are aware of men's risk of cancer in this area of their bodies, then they can impart this knowledge back to their male relatives and friends, and encourage them to be aware of this possibility. This may be of greater use than attempting to rename the illness. Women are aware of breast cancer already, and if knowledge about the disease in men could be added to awareness campaigns then this is likely to benefit men in the long run.

Masculinity and breast cancer: challenging individuals, or a community?

Breast cancer can be seen as creating and influencing different issues for men and women diagnosed with it, and also for creating different issues for individual men. Men, like women, are not all going to experience breast cancer in the same way. Focusing on the aim of this research, to explore how men experience being a breast cancer patient and how this is to be understood, in some respects men place the focus on an individual experience rather than a more communal one in the way women are seen to do. Women, and the wider breast cancer community, position men as marginal, and this is reflected in attitudes and opinions held by some men in terms of viewing their illness as perhaps less significant than the disease in women. Whilst this may be their opinion, it is arguably the social norms and values of the breast cancer community as a whole which has allowed such opinions to dominate.

One man, Mr Lowe, agrees that breast cancer affects women more than men, and believes he has not lost anything, as his focus is on putting his experiences behind him and to carry on getting healthy again (*The Hamilton Spectator* (Canada) 07/03/00). Mr House, another patient, thinks that losing a breast is shocking for men but:

‘nowhere near as traumatic as for a woman for whom it's the loss of a part of her personality as well as part of her body. Men just wind

up with a scar instead of a nipple and you soon get used to that.’ (*The Observer*, 06/25/00).

This quote shows how these men are able to reduce the significance of their illness, both to themselves and to others. Mr Lowe is concentrating on the future and does not believe he has lost anything, and Mr House believes his experiences, and those of men in general, to be less traumatic than for women. This forms the basis of what can be viewed as a catch-22 situation, if men do not see their breast cancer diagnosis as being significant in terms of trauma, lifestyle changes, and health, then other people and charities will not see it as significant, as they will see the male patients carrying on with their day to day routines with minimal disruption and change. In turn, because breast cancer in men is not viewed by charities and other organisations as being a significant challenge, male patients will perceive this and act in what they see as an appropriate manner, thus perpetuating the situation. This reinforces men with breast cancer as marginal, as they occupy a position which is viewed by both themselves and organisations as being less traumatic than the position occupied by women with breast cancer. For men to behave in a manner which does reflect the severity of the illness would be to move away from what is considered appropriate behaviour, thus challenging the perceptions and actions of others.

Similarly, Mr Goldstein never felt that breast cancer was damaging to his masculinity, but does acknowledge that it could be for others (*Evansville Courier and Press* (USA) 09/14/00). Regarding his mastectomy, Tom explained how it did not worry him as men can:

‘just put on a shirt and a jumper and that’s it. I don’t go round in a bikini or anything!’ (*South Wales Echo*, 08/13/09).

These quotes show that a breast cancer diagnosis is not the same for all individuals, and that people view themselves differently compared with how others may view them. What is considered a threat to masculinity by one person may not be by another, and as such men cannot be considered a homogenous group within the breast cancer community, in much the same way that women cannot be seen as a homogenous group either. This shows that how men experience being breast cancer patients is an individual

process, and needs to be understood as such.

Several articles contained quotes or opinions which suggested (or even stated) that a breast cancer diagnosis will affect a woman more than it would a man. In an article about a man who had breast cancer:

‘For a women, breast cancer is not just a terrifying disease which threatens her life, but a potential thief of her sexuality, self-image and womanly role as nurturer of the young. Female patients must contend not only with the physical aspect of their illness and treatments, but also the emotional loss’ (*The Hamilton Spectator* (Canada) 07/03/00).

From this quote, breast cancer in men is seen as a disease which can threaten life, but breast cancer in women is seen as something almost more powerful – even if a female patient survives the illness, so her life has been saved, she may have lost parts of herself, both physically and emotionally, during her treatment. This ‘emotional loss’ is something which is often missing when breast cancer in men is discussed, as for men, they are not seen as having breasts, with the associated connotations, in the way that women are. Women’s breasts are visible, and are associated with, for example, sexuality and motherhood. Men’s sexuality and fatherhood are not associated with breasts, indeed breasts are barely associated with the male body at all. (An exception to this is the imagery surrounding the character Tarzan, and his naked torso representative of strength and virile masculinity.) For a man to lose a breast, a part of his body of which he and other people were hardly aware, there is less emotion caught up in this procedure. In total, this all portrays breast cancer as a disease less threatening to men, as they ‘only’ have the physical side of their treatment to come to terms with. The truth of this can only been known through increased public knowledge and awareness about the illness.

Similarly, in an article about a man’s experiences playing a character in a television soap opera who has breast cancer, Mr Stahl said:

‘The traumas for women with breast cancer are more obvious – especially if it leads to having a breast removed. For a guy, any

resulting scar could be written off in time as some heroic battle wound. But the emotional trauma a man goes through trying to come to terms with the fact he's got what he sees as a 'woman's disease' it also very hard to deal with' (*The Sun*, 11/02/00).

There are a number of assumptions within this quote. First is that the traumas women with breast cancer face are already known, and so do not need to be specifically mentioned. Having a breast removed may be the obvious trauma, but other traumatic events and procedures are not referred to. The use of 'obvious' implies that for women breast cancer is a public, visible disease, whereas for men it is much more hidden and secretive. The work of Seale (2001b) explored the idea of a heroic metaphor in media articles on cancer, and how cancer patients can be described as warriors battling a life-threatening enemy, with any injuries and scars sustained in these battles being viewed as battle scars, reflecting the hero's battle with the enemy. The idea of a 'heroic battle wound' may appeal to some people's way of framing their breast cancer experiences, but for others there may not be anything 'heroic' about their mastectomy scar, whether they be male or female. Such a framing reflects strength in the face of adversity. Perhaps men are more likely than women to show their scars, but this does not imply that it is something which can be 'written off', an event which occurred in the past and has no bearing on the present or future. Equally, men may well suffer 'emotional trauma' as they have a 'woman's disease' but it could equally be interpreted that their emotional trauma is based on the fact they have been diagnosed with a disease which is life-threatening, with severe and invasive treatment options and no guarantee of a cure, and this has had more of an impact on their emotional well-being than the disease being seen as a disease for women. There has to be more to a man's feelings regarding his experiences with breast cancer than just the concern that it is a disease of women.

Masculinity and the dominance of women

Breast cancer being seen as a women's disease is shown throughout the threads on the forums for men with breast cancer, in terms of the dominant presence of women highlighting the relative absence of men. Presence can

be seen as both numeric, and symbolic. The numeric presence is shown through the significant majority of people using the forums being women, and the symbolic presence of women in terms of dominating threads and conversations, and participating in sections of the forums aimed at men. This is not necessarily meant to be viewed as a negative situation, as if women did not participate in sections aimed at men, then there would not be many users of these sections at all, but it does reflect how the absence of men is felt across these areas.

This presence of women is shown in a variety of ways, from female relatives of diagnosed men, asking if there are any men who would be willing to share their experiences, to women posting questions or queries on behalf of their male relatives, to men themselves wanting to share experiences, and hearing in reply mainly from women. One such example of a female relative posting whose husband has been diagnosed with breast cancer is on one forum,

‘My husband has been told he has b/c he had a mastectomy in 2 weeks’ time. I was wondering is there any other men on this site that has b/c.’ (*maureen*, British3, 14/04/11)

There are no replies to this, and two weeks later she posts again, asking if her husband is the only man on this site with breast cancer. In absence of a reply, she shares his illness story from diagnosis through to treatment. This post does get a reply, in which a woman says:

‘I am sorry you haven’t got a response – there are very few men with breast cancer and even fewer who use the site, as far as I am aware. That said, he will face many of the same issues we women face and is very welcome to join us – as are you, his main support [...] I guess for men, it is a bit more of an awkward and possibly embarrassing illness and people are inclined not to believe a bloke who says he has breast cancer. There was a chap having test at the same time as me, he was just as frightened as the rest of us’ (*Sally1*, British3, 06/05/11)

Referring to the 'issues we women [with breast cancer] face' shows a common illness identity, one which will be shared to some extent by both men and women with breast cancer. This illness identity, which people can identify with and share, means that women are able to comment on threads and posts aimed at men, as their experiences may overlap to some extent. Whilst men may find it harder and more complex to engage with this illness identity, there are elements there which are potentially universal, such as the author of the post describing a man undergoing testing at the same time being 'just as frightened' as she was.

Women posting in place of men not replying is shown in a thread on a British forum: it is started by the daughter of a man recently diagnosed, who writes that:

'from my dad's experience I have found out there is more information for women than men pre and post-operatively and he also said that when he went for appointments, my mum with him the consultant would always speak to my mum rather than to him even though he was the one that had cancer. I was just wondering if anybody on here would be kind enough to share their experiences, if you are male or know anyone who has or had breast cancer and also what and how you feel and the information there is available for men. I also found that when my dad had his mastectomy the aftercare info was mainly aimed at women.' (*lizzyapple*, British2, 02/12/10)

A request for inclusion and a sense of belonging is asked for here, as the author asks for someone to 'be kind enough' to answer her many questions and share their experiences. Kindness implies an idea of ethics, that people can positively help others. This individual is unable to access the information she needs, partly because this information may not exist, and as such she is appealing to the marginal group of men to share their experiences and help her.

On this thread, a woman is the first to respond, who says she has only ever met one man with breast cancer, perhaps to indicate to the OP that there are only a few people who are able to offer her the information she seeks. One man does reply, who is prepared to talk about his breast cancer experiences.

Whilst the OP may be supported and comforted through the posts received, as she specifically asked for men to contact her, again the reply from a woman highlighting how few men are diagnosed (a fact which with the OP is probably familiar) may only further highlight how absent men can be from breast cancer awareness and support.

On one thread, a wife whose husband has been diagnosed, asks:

‘just wondered if anybody else knows any man who has been diagnosed with breast cancer. We understand it is pretty rare.’
(*Helen57*, British2, 21/05/11)

The first reply comes from a woman who is:

‘so sorry to hear about your husband’s diagnosis. I can imagine he would feel quite isolated as it is quite unusual in men. From what I understand though the treatment is much the same. If you need any help or guidance re his treatment, or just general support, you have certainly come to the right place.’ (*mirror*, British2, 23/05/11)

This assumption, that the husband feels isolated, is once again portraying the relative absence of men. The assumption within this sentence is that because it is so rare, he automatically feels isolated. This may be compounded by the even fewer number of men who are active online. The OP has come to the forum to see if anyone knows of any men diagnosed, and so far only women have responded. Whilst this is supportive, it cannot help but highlight how no men have responded. To engage with these forums is to engage with a breast cancer identity, and men diagnosed may not be comfortable with this being a dominant part of how other people see them. For the OP, she does not have breast cancer as part of her identity but she does have her femininity, and it is this which is shared with the women who are responding. A commonality is constructed and maintained and this is required in order for there to be a community within these forums. As such, men either need to share and help maintain this commonality or remain as a marginal group.

This presence of women and absence of men is portrayed in a different manner when female relatives are posting specifically on behalf of their man with breast cancer. One wife writes that her husband has been diagnosed:

‘He is also embarrassed by the fact that it is breast cancer and so does not want to talk to friends about it. I am giving him all my love and support but I think he needs to be able to talk to other people affected by the same disease. Computer chat rooms are not his style, he’d prefer face to face groups, so I wondered if anyone knew of any breast cancer support groups with male attendees in [location]?
(*ConcernedWife*, British2, 08/03/12)

One man, whose wife had breast cancer, doubts that there are any specific support groups for men, partly because so few men are diagnosed with breast cancer, but also because ‘many [men] prefer to stay in the shadows’. Practical advice is offered by the next responder, who suggests asking the breast care nurse if they are aware of any meetings locally. The OP thanks the man who responded, for his offer of chatting online with her husband, and she will ‘make sure he knows you are there if needed.’ Here is an example of a woman acting as an intermediary for her male relative. This post also once again highlights the presence of women, as by asking to share experiences with others, she is assuming that both women and men are active users of this forum.

This presence of women, and the held assumption that women will be reading the threads, is seen in one thread started by a man who explains he:

‘would like to talk about breast cancer, treatment and effects with any similar MALE sufferers’ [emphasis in original]. (*gearchange*, British1, 01/08/08)

The emphasis on ‘male’ almost predicts that women will be reading the post, and willing to reply to it, even if they are not in a position to discuss the experiences highlighted by the OP. By emphasising this word ‘male’ the OP is being clear in what he wants: he is requesting to talk to people who are identifying as both male and also a ‘sufferer’, a word which is not often used on the forum (words which are neutral and more positive such as

patient, survivor, thriver, are used more commonly). This identity is a very specific one, which may only refer to a very small number of people. This message is posted in the men's forum section of the website, and highlights a potential discrepancy between what different users of the forums as a whole want. Whilst women may want to include men within their community, this is done through an encouragement which is gendered and as such can further separate women and men with breast cancer.

The definitions of masculinity/ies

The presence, and dominance, of women in the breast cancer community as shown above, has reinforced the feminine position as being central and dominant and placed men, and their masculinity, in a marginal position. How this masculinity (or masculinities) is viewed is relevant for the positioning of both men and women, and the ways in which they can participate within the breast cancer community.

Considering how female-focused breast cancer and its associations are, concepts surrounding gender were a key part of this research. The interview respondents were asked what the words 'gender', 'masculine' and 'feminine' meant to them. Richard, who had breast cancer, responded that to him gender means:

'just male female, that's all it means to me, doesn't mean anything more than that'. (Richard, 26/06/11, p.9)

In his interpretation of gender, Richard does not see a difference between the sexes, and that male/female is what it comes down to, and that there are no specific differences or traits associated with that binary. Paul, a recovering patient, answered that:

'some women are more masculine than others and some men are more feminine than others, so it's a sliding scale I would say'. (Paul, 12/05/11, p.4)

When asked the same question, Helen, a member of staff of a breast cancer charity, replied:

‘traits, so feminine might be pink or purple or sparkly and masculine might be sport or facial hair. Something like that.’ (Helen, 04/05/11, p.6)

Rosalind, another member of staff, was the only respondent who clearly differentiated between sex and gender,

‘I think people use the terms interchangeable really sex and gender, and I think you could argue that it’s, it’s sort of, greater than that, it’s about a sense of identity and, er, that perhaps a sort of biological definition doesn’t allow for.’ (Rosalind, 11/05/11, p.6)

The members of staff interviewed were reluctant to define gender and what it means to them, whether in a personal capacity or from their role within the charity. Whilst admittedly gender is a difficult term to conceptualise, it is odd here that from an organisational point of view, there is not a working definition of the concept. The experiences of Star (1991) and her unusual allergy to onions show that in the context of production in fast food restaurants, there is only a problem with the production when there is an unexpected situation. Relating this to breast cancer organisations, it is this unusual situation of men with breast cancer which has shown the potential problems in not fully considering the role of gender. Star’s requirement to have food separately prepared in such a regimented environment means the restaurant struggles to adapt to her needs, especially when they know they are unlikely to have a similar problem again for some time. This form of marginality is shown with men entering the breast cancer community, which as a whole is not prepared for their needs. Breast cancer organisations are aware of how rare breast cancer is in men, and so any adaptations or alterations made are unlikely to be used regularly. Any accommodations also need to allow the procedures and processes in place for women to continue operating, further entrenching men’s position as marginal.

Seeing as how breast cancer is a disease which has such strong gender-based connotations, there appears to be room to suggest that conceptualising a

definition of gender could potentially benefit the formation and utilisation of policies. This could have the potential to make such charities seem more accessible not just for men diagnosed with breast cancer, but also women who do not fit the 'typical' mould of a breast cancer patient. Breast cancer awareness campaigns often show women with the disease as being middle-aged, heterosexual, positive in their attitude, and supportive of charity work and involvement. Whilst this is a generalisation, many women will fit this description, as it is one which portrays a positive message about the benefits of fundraising, awareness and research. However others may be put off by such a description, for example women with secondary breast cancer, or gay women who may relate to their breasts in a different way. Therefore, moving away from a 'typical' mould could make charities and support organisations more welcoming and accessible to a wider range of people, as it may not just be men who are marginalised within the wider breast cancer world.

Rosalind argues 'it is hard to say exactly what gender means' and elaborates that:

'I suppose I feel slightly uncomfortable with masculine and feminine because I think they, they force you to go down the quite erm, they make me think in quite a stereotypical way, you know they make me think blue and pink and sort of roles that men and women are supposed to do, and not supposed to do, and, so they make me think of sort of conforming type idea of what a man and a woman is but you could also argue that what they mean are you know sort of likely traits or tendencies that men and women have that are different I suppose.' (Rosalind, 11/05/11, p.6)

Rosalind's quote reflects a balance between the structures imposed on her by her work environment, and her own agency and opinions. She acknowledges that the broad terms of 'masculine' and 'feminine' make her feel uncomfortable but she does define them in a way which she herself acknowledges as stereotypical. This is in contrast to Michael, above, who whilst he probably is aware of these stereotypical definitions, refused to acknowledge them and just said he saw no difference between 'male' and 'female'. The charity for which she works fully embraces the colour pink

throughout their organisation, which firmly fits within the stereotype of an organisation for women being pink, the 'feminine' colour. If Rosalind is uncomfortable with this, she is aware of her position within the charity and how she needs to be supportive of its aims and objectives: she cannot ignore the overt pinkness of the charity, yet she can acknowledge that this is a stereotype, and women and men need no long be seen in such traditional ways.

Barbara, a staff member, argues:

'there's a heavy social construct to gender which is both useful in terms of understanding how important it is to people but it [is] also linked to stereotypes and unhelpful ways of thinking about people.'
(Barbara, 13/05/11, p.3)

She later acknowledges that 'obviously you can have a big diversity of experiences and identifications out there,' (Barbara, 13/05/11, p.4) highlighting the fact that the people who contact the charity are individuals, and that whilst many will meet a 'feminine' ideal that is perhaps effused (unintentionally or not) throughout such an organisations, many breast cancer patients will not. The question to be asked is: what provisions are made for them? There is a cultural convention here reflected by both Rosalind and Barbara, in that they are both aware of how they should respond to questions in order to accurately reflect the charity for which they work. Both women acknowledge how unhelpful and often inaccurate gender stereotypes can be, but equally they both indicate such constructions can be useful in terms of framing aims and goals of their employer. If these women, or other people, feel that such a stereotyped attitude towards gender is reflected in the institution, they may wish to change this, but such a change would be monumental, and involve lengthy negotiations. As such, it may be a better use of time and resources to retain the stereotypes, and just acknowledge their presence when required, in a way which is not seen as detrimental to individuals or the organisation as a whole.

Breast cancer charities have, to some extent, a one-size-fits-all policy, even though as organisations they may be aware that this will not be suitable for everyone who is involved, or wishes to be involved, with their charity.

Whilst there is in part an acknowledgement of differences between individuals, as shown by comments from the staff members above, the main emphasis is still very much on the majority group. As such, charities are aware of being deeply gendered (through being focused on a specific idea of women and femininity) but are often unaware of the extent of the impact this may have on current and potential users of their services, as well as when considering future services and events.

Developing this situation of being deeply gendered, breast cancer charities can be seen as being aware of gender in terms of different types of femininity - staff member Barbara above acknowledges the social construct of gender and how such stereotypes can be unhelpful, for example with not all women wanting to embrace the pink colour scheme so strongly associated with the disease. In this sense, charities can show how they are deeply gendered, but also reflect a certain element of being gender blind in terms of welcoming and including men – it is acknowledged that women will have different ideas and values, and so not all women will wish to affiliate themselves with such a culture within the charity. However, men are barely included in this at all: if they are included it is as another group which does not fit within the dominant framework, when arguably they are within a different group entirely and it is this which is not considered.

Conclusion

This chapter has shown how receiving a breast cancer diagnosis challenges hegemonic masculinity in a number of ways. As a starting point, the work of Bury (1982) on biographical disruption explores how individuals diagnosed with a chronic illness find themselves in a position where their everyday life has been disturbed, and as such they need to discover what effect this will have on how their biography is viewed by both themselves and other people. However, the assumption is that people will be able to do this, due to the information, resources, and support currently available. For men diagnosed with breast cancer, this assumption is misplaced, as the process is less straightforward due to the general paucity of specific knowledge available to them, as well as the fact that the production and reception of this information is largely gender-based, meaning the focus is

on women producing knowledge for other women. As such, the theoretical tool of biographical disruption is not sufficient to fully explore the challenge breast cancer presents to men, hence the value of incorporating Park's idea of the marginal man, allowing men diagnosed with breast cancer to be seen as part of the wider breast cancer community, and yet on its outskirts.

Data from all three datasets showed how men being diagnosed with breast cancer, and their subsequent treatment, challenged the sense of hegemonic masculinity. The majority of men in this research were unaware of the possibility of receiving such a diagnosis in the first place: this lack of knowledge placed them in a position more vulnerable than that associated with hegemonic masculinity. This was compounded by the lack of male-specific information available, meaning men no longer had control over their situation as the knowledge needed was not there in order to make informed decisions about how they progressed. This is significant as it shows men experience being a breast cancer patient in a way which is marginalised from the beginning, due to the lack of awareness and the lack of information. This hinders their ability to participate within the breast cancer community, as so few people expect them to want to join, in terms of moving away from how they may be perceived as embodying hegemonic masculinity. In an attempt to address this, media reports and public campaigns ought to try to move away from an idea of exclusivity, of breast cancer being only for women, as it has potentially neglectful consequences.

This situation of men not having control over, or knowledge about, their experiences, reflects Star's idea of being uncommon, and its effects. Social groups and social worlds are often not prepared for the specific needs of rare groups of people, as Star demonstrated through her experiences when requiring fast food restaurants to accommodate her (unusual) onion allergy. This is especially true when the needs of the more common group(s) of people still need to be catered for, alongside the minority group. It has shown to be difficult to address the needs of men as the minority group of breast cancer patients, in a way which does not detract greatly from the needs of the majority patient group, who are still the main users of services. This shows a mechanism by which men find it harder to participate within the breast cancer community, as the systems in place marginalise men, and

it is complex to adapt these systems in a way which makes them more inclusive.

The focus the breast cancer community largely has on this dominant group of women was apparent throughout the datasets. This challenged hegemonic masculinity by placing men in a position in which they were marginalised and removed from the dominant group. This dominant group was hard to penetrate, due in part to the lack of awareness about breast cancer in men, and also in terms of the lack of knowledge about breast cancer in men generally. These findings are significant as they show the mechanisms through which men are less able to participate are not solely due to the behaviours of individuals, but the standards of the breast cancer community produce inclusions and exclusions. As the work of Star shows, standards used, and the tools used to create these standards, are a feminine way of viewing breast cancer as the majority viewpoint is continuously being reproduced. This paucity of awareness and knowledge impacts upon men's changing identity, and how men negotiate their changing evolving identities, and how other people perceive them, is the focus of the following chapter.

Chapter Five

How men with breast cancer negotiate their identity in the wider breast cancer community

Introduction

The previous chapter explored how the receiving of a breast cancer diagnosis for a man could threaten hegemonic masculinity, in terms of how the individual perceives himself, and also based on the perceptions of others. The work of Bury (1982) and biographical disruption was seen as not being sufficient enough for investigating how men with breast cancer reorganise their biography following diagnosis, and how the marginal man theory developed by Park (1928) is well situated to further this exploration.

As a sociological theory, marginal men as devised by Park building upon Simmel's (1972/1908) idea of the stranger, originates with the study of immigrant as they try to belong to the culture of the new country in which they find themselves. They want to be involved with the new country and community in which they find themselves, yet they still share in values, aspects and attitudes of their first culture and country, and as such find themselves in a position in which they are marginal to the dominant group. They are unlikely to ever become a fully-fledged and accepted member of this dominant group, as they have certain characteristics which are unable to be shared with the norms and values shared by the majority. This chapter explores how men with breast cancer negotiate their identity in terms of beginning their membership of the wider breast cancer community. Park positions marginal men as having a double consciousness, and these men with breast cancer are starting to experience this when coming to terms with their illness.

Whilst not in a new geographic area, men diagnosed with breast cancer find themselves on the outskirts of a new culture, with its own institutions, organisations, and related norms and values. Their acceptance into this new culture is hindered by their unusual characteristics, their gender standing out

amongst the overtly feminine environment. Star (1991) positioned unusual characteristics as posing a challenge for the institution with which they became involved, as institutions hold normative assumptions that are questioned and critiqued by the presence of anything seen as different. It is these normative assumptions held by institutions that reinforce the position of men diagnosed with breast cancer as being marginal. For breast cancer, there is often a split between illness and gender, as emphasis placed on femininity may ease entry into the breast cancer community, creating a shared illness identity, but this is harder to approach from an illness identity point of view, in which people are patients first, and their gender second.

To some extent, the experiences of any individual diagnosed with breast cancer are going to be unique, as people have a variety of different personal experiences, which go towards building their biography and forming them into the person they currently are, which must have an effect on how they approach their identity as breast cancer patients. This chapter explores how men with breast cancer negotiate their identity within the wider breast cancer community, and how their experiences of participating in the condition group reinforce their marginal position yet provide them with a privileged viewpoint from which they can highlight the assumptions and behaviours of the social institutions within this breast cancer community. Ideas of masculinity and femininity are investigated, focusing on how masculinity and femininity are perceived as constructs, and how these reinforce women's dominant position within the breast cancer community, thus firmly positioning men as marginal. Alongside this, a breast cancer diagnosis will impact upon a person's identity, and this diagnosis will need to be negotiated into how they are viewed by themselves and others. This identity management is linked to involvement within the breast cancer community, and for men to become active, accepted participants within this community, their identity needs to be negotiated in such a way that it is their illness upon which is focused, not their gender.

Experiences of participating in the breast cancer community

Data analysis across data sets often showed that men experienced participation within breast cancer groups, meaning actual breast cancer

support groups as well as simply finding themselves within the breast cancer community as a larger whole. One theme which is apparent throughout the data is the role support from friends and family members play in terms of helping men and their changing identities. In terms of negotiating identity, men need to establish how their roles in life may develop in the future, and alongside this the potentially changing roles of their family and friends. Such evolutions need to be successfully managed and maintained in order for a successful negotiation. There were several key differences shown in terms of how women and men participate in such a community. The shared breast cancer diagnosis brought men together to this community, but women seemed to focus on their shared gender identity primarily, indicating the inherent tension between gender identity and illness identity. Both men and women appreciated being able to share their experiences with others, but for men this was much harder due to the lower numbers of men diagnosed, and the difficulties faced in terms of access. Men often wanted, and asked for, support specifically from men, and yet for many individuals it was women who replied, even if they lacked the answers to their questions.

The sense of a wider community is shown when a young man diagnosed with breast cancer says:

‘it would be great to hear from you all’ (*changes30*, British1, 19/11/07).

The first reply is from a man, who shares personal experiences about his treatment, and tells him that the forum will provide help. The original poster responds that:

‘it’s nice to be able to talk and be able to express myself with fellow sufferers’ (*changes30*, British1, 20/11/07).

This man is identifying himself as a breast cancer ‘sufferer’ and acknowledges that he appreciates being able to share this with others. This idea of sharing with others forms the base of identification, as he has found people who share an identification similar to his. However, what is not expressed here is whether he is using their shared illness, or their shared gender, as the key basis for this shared identification. Whilst he is posting

on a thread specifically for men with breast cancer, thus implying gender is key here as the post is not online elsewhere, by writing that ‘it would be great to hear from you all’, and women are active users of this part of the forum, there is an identification that it is their shared diagnosis which brings them together. As such, the users of the forum in this case are focusing on their identity as sharing an illness. However, illness is not always the shared basis for identity on these forums; many posts as discussed above have shown that men have had to engage with a more feminine gender identity in order to fully participate within these forums, especially if they do not wish to have themselves defined by their breast cancer. This reflects the tension inherent in having a gender identity and an illness identity, and how an individual wishes to focus this will impact upon how they later participate in forums and the wider breast cancer community. Both men and women ought to focus on a shared illness identity, in order to gain as much as possible from one another in terms of their shared situations and experienced, but it is people’s individual gender identity to which they may be more strongly attached, thus influencing their willingness to accept others on the basis of a shared identity which is seen as secondary to their gender.

One key topic within the datasets was the support and involvement of friends and family which was described as important by the men diagnosed with breast cancer interviewed, with Michael affirming that:

‘you’ve got to have a strong marriage to get through breast cancer’.
(Michael, 07/05/11, p.23)

This implies that breast cancer can be seen as a threat to a marriage, and also to the identity of the patient as being part of a married couple. In relation to biographical disruption, a breast cancer diagnosis could change the roles and relationships people have and share with one another, and not solely disrupt the life of the patient. Therefore strength is required from both people involved in order to maintain this element of their shared biography.

Being a man diagnosed with breast cancer affects the people around him, as shown by the quote above, and as such as it important for charities to be

there in a supportive capacity for these people also. Helen, a member of staff at a national breast cancer charity, says:

‘we’ve worked hard to try and get families, friends, and um, try to get them involved with our services’ [but she acknowledges that] ‘because there are so few men out there it’s sometimes hard to get things off the ground [for friends and family].’ (Helen, 04/05/11, p.6).

Because relatively few men are diagnosed this impacts upon not only the care and support available for them as a minority, but also for their support network.

As she works for a medium-sized charity, Barbara states that they have to discuss ‘how much [we are] there for and trying to support families as well as the person themselves’ (11/05/13, p. 7). Helen points out that the families and friends of men diagnosed with breast cancer:

‘can access all of our services um, help, help, particularly the helpline and ask a nurse service and any of our written information and we would encourage them to do that [but she imagines that] ‘it’s very very difficult for them dealing with their partner depending on the personality of that person’ (04/05/11, p.12).

Here, the involvement of partners can be seen as depending on the willingness of the men with breast cancer to become involved with charities and organisations themselves. If a man does not want to become involved with the wider breast cancer community, this may restrict the involvement of his family and friends, as they may not want to position him within this community if it is not somewhere that he is happy to place himself. If he has not incorporated a breast cancer identity into his sense of self, then for other people to do this almost of his behalf, would run the risk of alienating him from how he wishes to be seen by others. Even if this is not the preferred level of engagement for family and friends, it may be more beneficial for the man in the long term to not have his identity and self-perception altered by others. The forums include a large number of women who ask questions on behalf of the men they know diagnosed with breast

cancer, the relative anonymity providing them with an opportunity to become involved with the wider breast cancer community in a way which is seen as less detrimental to how the man may view himself.

In relation to being in a position from which to offer help and assistance to others, Paul was contacted by his cancer nurse, who:

‘rang me up and said ‘I’ve got another man, would you talk to him?’

I said yes, no bother. It’s another link, if you look at it, someone else to care about and someone else to care about you, every little helps.’

(Paul, 12/05/11, p.19)

Being able to talk to another cancer patient can be of benefit to both people involved, allowing experiences to be shared and advice sought, especially if the people are at different stages following their diagnosis. As there are so few men diagnosed with breast cancer, being able to talk to another man in a similar position is not always practical (especially when compared with the ability of women being able to talk to other women), and so may involve effort from a number of medical professionals and charities in different geographical areas. This effort on behalf of Paul, being willing to talk to a stranger about his diagnosis, reflects an additional person being able to care about them, and help them with any questions they may have. Relating this to Park’s marginal man theory, not being able to talk to another man with breast cancer further marginalises these men. Being on the outside of the majority group, these men are unable to access resources with the same relative ease as women. They are also isolated from other men as the network is not firmly in place to connect easily with other men with breast cancer. However, for those who are willing and able to talk to other men this has the potential to help people feel less isolated, and part of a wider community, even if that is a community marginalised for a majority group.

It is often apparent on the home pages of the forums themselves that their predominant aim is to provide support for the people who use them. Practical support was asked for and provided in a number of ways in these forum posts. Practical support can be defined as the presentation and exchange of useful advice (for example, how people dealt with different side effects of treatment); and suggestions, such as specific organisations to

contact, or exploring what worked for different individuals. Asking for advice was quite common. One woman on a British forum posts that she is seeking advice ideally from any younger men who have had a similar experience to her young son, who has found a lump under one nipple. Here there is the assumption that the people reading the forum will have the relevant experiences and answers. There perhaps is no other source of information through which such experiences could be shared. The first responder says he is not young but had a similar experience, and another man replies and gives a directly relevant answer. Within this is the idea that even if someone's experience is not directly relevant to the question asked by the OP, it is still appropriate, and indeed encouraged, to share similar experiences. This can be linked to the work of Borkman (1976) and experiential knowledge, focusing on truth learned through personal experience within a given phenomenon, as opposed to truth which one acquires through the learning of information given by others. It is knowledge which can only be gained through personal participation, and cannot be seen as solely facts which an individual has not considered, there needs to be an element of reflection and personal experiences. The original poster of this thread is specifically seeking experiential knowledge, whilst she may obtain more medically accurate or factual answers elsewhere, the desire for advice from young men shows a yearning for individual insight and information which has been considered in its application before being passed on to others.

Focusing on the forums more specifically, many of the posts on these forums are written by, or on the behalf of, people who are currently undergoing treatment, or who have come through breast cancer treatment. Undergoing treatment for breast cancer is intense, and it is this intensity which can impact upon an individual's sense of self. Before treatment, it may have been possible for the individual to not be defined by their diagnosis, as to some extent daily life could be unaltered. However, treatment such as chemotherapy requires, among many things, hospital attendance and time off work, both of which may alter how they see themselves and how they believe they are perceived by others. The treatment may now be a key factor in their sense of self, especially if it is early on in the treatment when perhaps individuals have not yet fully incorporated their breast cancer diagnosis into how they see themselves.

These changes to self may be hard for people who have not experienced it to understand, and so forums provide an environment in which people may be able to find others who have been in similar situations, showing once again the role of experiential knowledge in building a supportive and mutually beneficial environment for its members. These threats to changing identity are likely to impact upon friends and family members of the individual diagnosed, as they too undergo changes as they shift and alter shape in order to incorporate the changes made by the patient.

In line with the idea of support, there is the idea of being there for someone, even if that person has no advice to give. This is illustrated by a woman who replies to a man on one British forum who asks about side effects of a certain drug. She says she is not on that drug, so cannot share experiences, but suggests a possible alternative reason for the cited side effect as she:

‘just wanted to try to help you’ (*ForumMember*, British1, 01/01/08)

The original poster thanks her for the comment, and the next commenter feels that it helps just knowing another person is thinking about them. Here is an example of social solidarity in action, in that by joining together with people who share a similar identity are able to be cohesive and work together to support one another. By identifying with other people in this social group and context, ‘knowing’ that ‘someone else is thinking about you’ allows the individual to feel they are less alone, strengthening social support through experiential knowledge.

In a similar manner, one man posted on a British forum explaining how:

[he has] just been diagnosed with BC and would like to get in touch with any other men out there who are in the same boat with a view to set up an informal help group. (*Eddie9*, British1, 23/01/10)

Here there is a specific requirement for experiential knowledge, as not only does he want the support from a group, he would like the benefit of experiences of others in order to share for the benefit of the collective group. This post receives, however, replies from three women,

Hi Johnny, sorry to hear your news [...] How are you feeling? Quite a shocker isn't it, life knows how to kick you straight between the legs at times, yep even females feel this one! Anyway, don't not visit us, keep in touch (*Toadstool*, British1, 23/01/10)

Hello Johnny, I hope you soon get responses from men in the same boat as you, but welcome to the forums and remember where we are if you'd like to discuss anything we might be able to help you with (*flowerpetal*, British1, 23/01/10)

Stay on touch with this thread, it will help you. Ask anything you want (*Jessica*, British1, 23/01/10)

These posts are all offering words of emotional encouragement and support ('keep in touch'; 'remember where we are if you'd like to discuss anything') but they do not directly relate to what the original poster asked for. He asks if there are 'other men out there' who would be interested in setting up 'an informal help group', and the replies are from women who are not able to provide information he needs on men willing to participate. Whilst the messages are supportive in their content, by not being able to address the needs of and request from the OP they are reinforcing his status as a marginal man as they are highlighting how alone he is in terms of people diagnosed with breast cancer. The multiple comments from women (their gender is presumed female from their username or through something they have written) further highlight the numerical difference between breast cancer diagnoses in women and men. Some threads involving male posters could have weeks or even months between replies, as so few men use these forums. With this post, there are many replies all on the same day, again showing the dominance of women on this forum. This is another way in which the marginalisation of men with breast cancer is displayed, although undoubtedly the women posting in these threads would not wish to consciously marginalise these men any more than they already are.

Medical research

With regards to practical support, some posts ask for specific information, and provide a detailed background to their question. Often this involves medical language and scientific information which is likely to be something with which people who have not experienced breast cancer are unfamiliar. Inherent in this idea is the assumption that the population reading these forums does have this knowledge to be able to give an intelligent, appropriate reply. To possess knowledge is to be familiar with a given situation or object, and includes knowing facts as well as skills, which are gained through both education and experience. Users of the forums often use terminology and abbreviations which would be unfamiliar to many people, and therefore assume that other people using these forums have encountered enough similar experiences or education in order to be able to understand and respond appropriately. One can only fully participate within this breast cancer community (although it would apply to any community which assumes a certain level of knowledge regarding a specific subject) if one has encountered certain situations which have required them to develop their understanding in this area. The accumulation of this knowledge is a necessary step an individual needs to undertake in order to be able to fully participate with others.

This relates directly to the work of Star and knowledge standards. Social worlds, such as the breast cancer community, create and use standards which can become rigid in their implementation, meaning a sense of inclusivity and exclusivity is developed. The men with breast cancer, who are in a marginal position, understand this as their privileged viewpoint means they can see the standards being used, for example the tools used to diagnosis and treat the disease are a feminine way of looking at the illness. Standards have a politics, and the medical research and knowledge surrounding breast cancer (and the lack of male-specific knowledge) demonstrate its importance in terms of understanding men's experiences of being a breast cancer patient and how they are less able to participate within the breast cancer community.

One post relying on the shared experiential knowledge and understanding of others within the community is a man asking if there are any men on the forum taking aromatase inhibitors as:

‘unfortunately for us male breast cancer patients, there is very little information published on this matter’ (*Irarebird*, USA, 19/12/09)

This lack of published research and information reflects another aspect in which men are marginalised. Due to the paucity of male-specific information men are excluded from this breast cancer knowledge base. Clinical trials around breast cancer in men are unlikely, given that the number of participants required for the validity and reliability of a clinical trial is much higher than the number of men who are diagnosed with breast cancer. This means that medical information about breast cancer in men is based on data from clinical trials with female participants. Whilst, for example, some side effects may occur in both women and men, the lack of knowledge available which is specifically about breast cancer in men means that male patients do not have the same information in terms of risks and benefits that women have available. As such, men are not able to be a part of the breast cancer knowledge base, through no fault of their own, meaning they are marginalised from this medical knowledge and understanding. This reflects the importance of different forms of knowledge: there is the medical and professional knowledge about breast cancer from which men are excluded as they are generally unable to participate in research. However, there is also experiential knowledge, which is what is asked for here in the above quote – the man is asking for the experiences of other men, as there is no official information available. Many doctors may never see a case of breast cancer in men, due to its rarity, and so men diagnosed with the disease have to rely on the experiential knowledge gained by men in a similar position to themselves, as sharing their experiences is currently one of the only ways they have available to discuss, for example, side effects of treatment options, and be able to expand the knowledge base of breast cancer in men.

Referring to the quote in the above paragraph about asking for help, a respondent suggests another forum member by name who may be able to answer his questions. Even though this respondent does not have the knowledge or experience required to answer this question, through the sense of community and friendship built through the forum they are able to pinpoint someone who might. The OP thanks them for this message and says ‘being a male, sometimes I get to feeling like I am alone on this breast

cancer boat' but he feels better knowing there are other people available. There is one detailed reply from a man, who gives a succinct answer to the questions asked, explaining how doctors do not know in depth which treatments are most suitable for me. The OP thanks him for this and posits that 'it look like as with so many other things with male breast cancer and the lack of basic research on men, the doctors don't really know what to do for us.' But he does acknowledge that as there are so few men diagnosed there are not going to be sufficient people to partake in clinical trials. The man who answered his question suggests that:

'since so few men get breast cancer, and even fewer are ER+ [this relates to the use of AIs], I doubt that either a drug company or the government will ever fund a study of aromatase inhibitors in men.'
(*Rob55*, USA, 30/12/09)

The apparent justification for the 'doubt' that there will ever be research into this very specific area is that there are so few individuals who would fit the research criteria, perhaps even fewer who would be willing to participate, and therefore the research would not be viable. However, rare diseases and illness conditions do have research conducted into them: while they may only be relevant to a small subset of people, they are still of relevance. Whilst the implication within this post is that the number of people relevant for such a study is too small, small groups of people with rare diseases do obtain funding for research. Men with breast cancer do not appear to be challenging the medical establishment, though. There is an acknowledgement that only a few men are diagnosed with the disease, and this means that clinical trials and other forms of medical research are often more difficult to conduct, but this shows almost an acceptance of how the situation is currently. Only through challenging this, and making the voices of men heard, will professionals and the public be able to understand what it is like to be a man diagnosed with breast cancer, and how they can be better served within the wider breast cancer community.

With reference to the previous quote, this individual poster later comments to the OP that:

‘I’m sure you can appreciate how good it is to be talking/communicating with someone who has been going through this maze of treatment options of male breast cancer.’ (*confusedhere*, USA, 15/04/10)

If people do find it so useful to be in communication with people who have had similar situations, then breast cancer groups may not be working in this regard as fully as they could. Women as the majority group are able to find the information relevant to them with much more ease than marginalised men, and consequently, forums which allow individuals to communicate with one another theoretically provide men, and other minority groups within the breast cancer community, with the opportunity to find someone who has been in similar situations. Internet forums provide the ideal ‘ground’ in which to do this as the lack of physical restrictions mean that in theory more people are accessible. However, if this is so, then breast cancer groups are not working properly with regard to bringing people together to share experiences, as men are still not necessarily going to find someone whose experience matches theirs. Whilst this is partly a case of low numbers, and also fewer people willing to participate, the marginalised position in which men find themselves means that information may be harder to locate and then utilise, a situation which women in the majority group may not experience.

On a British forum a mother writes about her son who has just been diagnosed with breast cancer. She hopes:

‘you don’t mind me writing on your site’ (*dorothy48*, British1, 24/03/08),

implying that this forum is for the use of men with breast cancer, and that perhaps other forums are available for other users. Talking about her experience supporting her son, she has a message of being brave, and ‘never stop fighting, you can do it.’ She ends her message with ‘thank you if you read this, hope you weren’t bored, just my story.’ She is not actually posing a question or making a statement, she is just offering her story, perhaps in the hope that it can help other people. The first response is from a lady who says:

‘I often think about the poor men who get breast cancer and how they must cope with a disease that is very rare to them.’ (*ForumMember*, British1, 24/03/08).

The OP writes with regard to the support she has received saying she:

‘didn’t really expect it as there isn’t really much support for men with b/c so rare.’ (*dorothy48*, British1, 25/03/08)

There are many people using the forums, and whilst it may be harder to talk to people with specific experiences, especially if they are more unusual, there are people who can offer support on a broader level. However, posts often ask a direct question, and highlight that the specific information they require is not available. This shows that whilst there is not necessarily a lack of information, the information which is available is gendered in how it is made and used, in terms of its focus on the majority group of women and how it is utilised for and by them. This reflects gaps in the knowledge, further highlighted when people ask specific questions which cannot be answered.

The presence and role of emotional support

Emotional support is clearly in evidence when someone posts about their cancer being incurable, and derives from experiential knowledge. A husband posts that he has just been told his cancer is incurable and asks for any help or suggestions as he has some decisions to make. In bold, he writes: ‘I feel so alone!’ (*360turn*, USA, 21/04/10). The first reply provides a link to an article about living with stage IV breast cancer, and ends with ‘know you are not alone’ and that there are people to be there ‘every step of the way’ (*Philadelphia*, USA, 21/04/10). The next reply is also an internet link, showing both practical and emotional support. There are a few more comments offering support and personal experiences. It is this experiential knowledge which is required in order to give the effective emotional support needed by the original poster. The two replies include internet links with information about end-stage breast cancer, and whilst the original poster

may have been able to find these online resources himself, as he was able to participate within the forum and wider breast cancer community this work was done for him by people who knew what he was looking for. With one reply saying there will be people there for him ‘every step of the way’ he is able to share this wider community and know that there are people who are in a position to support him, with an understanding that perhaps friends and family members do not have, despite their closer position to him. Here, the man who started this thread is reflecting his double membership, in terms of being within two social groups and positioned on the margins of the dominant social group. There is a sense of community, in that people have replied with helpful advice and reassuring him that they will be there to help him. However, his opening declaration of feeling so alone indicates his firm position within the marginal group as there are so few people in exactly the same position with whom he can interact.

A man writes on a British forum that he is feeling low, especially due to the time of year (Christmas). The first reply is from a forum moderator who advises him to call the helpline. This shows that the charity is moderating the forums and clearly cares about the people who use it, thus again showing the nature of support, both from the people who use the forum and from the people who run it. The first reply from a user commiserates with him that he is feeling bad, but reminds him: ‘life is a battle worth fighting for’ (*MattM*, British1, 17/12/07) and people are available to give him moral support. Two users give practical advice and offer other websites to contact. The OP thanks people for their comments and says that people around him do not necessarily understand breast cancer. As the people around him do not share the breast cancer part of his identity, there is an idea here that people in real life cannot, and do not, have the knowledge and experiences that people on the forum do, and that therefore what is needed is an environment in which people who do share this illness identity are able to communicate. The original poster declares:

‘the good thing with this site is you know you’re going to get the support even when it’s nothing to do with the old B/C’ (*driver*, British1, 18/12/07)

Another user agrees:

‘this site is all about being able to talk without being judged or explaining yourself to folks.’ (*dh345*, British1, 18/12/08)

He says he (the original poster) has been supportive to others in the past, so people are only returning this to him. This reflects the notion put forward by Armstrong, Koteyko, and Powell, in that the

‘emerging body of literature on online health communities in general supports a model of ‘empowerment within limits’ where the individual user has the opportunity to feel more competent or in control through the peer-led exchange of information and emotionally supportive messages, within the cultural constraints of the particular community being assessed’ (2011: 348-9).

By sharing information and experiences, people are able to be empowered as they gain from the experiential knowledge of others, especially beneficial for people with an illness such as breast cancer in men, about which relatively little is known medically. In the thread mentioned above, the forum users have the potential to be empowered through sharing and receiving information, information which may not be available to them through other social relationships. The informal setting of a forum rather than, for example, the formal setting of a hospital means that they can feel more in control over their situation.

The use of a forum, which is away from the medical establishment, allows the users to be in control, and decide upon the topics and areas they wish to discuss. There are, however, constraints alongside this relative freedom, as expressed in the above quote. The breast cancer community is one which largely focuses on women giving support to other women diagnosed with what is seen as a ‘women’s disease’ and it is from this that the constraints within the community can develop. Men less able to participate, due to the small number of men diagnosed with breast cancer, and the even smaller number of men who already participate, and so their scope for empowerment is lowered, due to the constraints imposed inadvertently on them by the majority group. This once again shows men’s double membership: they are part of the breast cancer community if their illness is

focused upon, but if their gender identity is seen as paramount, then this is much harder to be fully accepted. As such they occupy two worlds, and are not able to fully participate within either.

The role of support groups and forums was apparent in the newspaper article dataset, with the importance of support groups outlined by Mr Buchel, who was diagnosed with breast cancer and had help and support from his family, and a support group. He said:

“The support group helped me a lot because I received absolutely no support or help from the medical profession...they had no idea at all about male breast cancer. According to my surgeon, I was the first male patient he had ever had. I met with the support group a lot while I was having chemo. I was so sick and it was hard for people around me to understand what I was going through. It was a comfort to talk with others who were in the same situation. There was one other man in our group so it was good for both of us.” (*The Courier-Mail* (Australia) 08/30/02).

What is important here is the general lack of information available. It may be assumed that if more information were available (whether that be from medical professionals, or charities) then perhaps men who would have less of a need to participate in female support groups. This lack of information is not only impacting on men, but also on women who may benefit more from single-sex groups. Ideas of support are key within charities and Stuart Gilder is ‘applying to become a Breast Cancer Care volunteer to help other men in the same unexpected predicament’ (*The Observer*, 06/25/00). Similarly, Mr Zimmer ‘received first-hand information and support from a male breast cancer survivor in the area’ and he is trained to offer support to others (*South Bend Tribune* (USA) 09/30/04). Two other men are working with charities and support groups in the hope that more options will be available for men diagnosed in the future as opposed to when Mr Yeandle and Mr Crew received their diagnosis (*The Globe and Mail* (Canada) 11/13/01). Alongside this willingness on the behalf of individuals to get involved with support groups is the desire to help others, even if the individual themselves did not seek that form of support. Mr Hadfield has noticed since his diagnosis:

“that there is not enough information about breast cancer in men. I want to rectify that. I didn’t need counselling myself but there must be other men out there that do” (*Lincolnshire Echo*, 11/02/02).

There is the expression of almost a duty here, that people should do what they can to ensure that others can receive the help and information they need throughout their breast cancer experiences, especially given the female-focus of the knowledge and literature available. Men are less able to participate in the breast cancer community than woman: if more men are able to help one another then this could have a positive impact on how men experience being a breast cancer patient.

Idea(l)s of masculinity and femininity

The concern about the lack of appropriate information for men in terms of breast cancer awareness, diagnosis, and treatment linked in across the datasets with ideas surrounding masculinity and femininity, and how these impacted on people’s experiences of breast cancer. Masculinity and femininity were explored in the previous chapter, in terms of how masculinity is positioned within a world that has evolved and been developed by and for women. This section explores how characteristics of masculinity and femininity were seen as impacting upon the perceptions of the individual men, in terms of how they see themselves, and how they believe they are viewed by others, especially in the context of giving and receiving support within the breast cancer community.

Many newspaper articles gave reference to support groups, with several men feeling excluded from breast cancer support groups in their area, which compounded their already heightened feelings of isolation, something which could negatively impact upon their health. Mr Scott, a patient,

‘went to a therapist twice, trying to deal with his depression. The counsellor suggested he join as breast cancer support group. “Are there any men in the group?” Scott wanted to know. He called around, but couldn’t find a single group that had a male member. He

didn't think he could relate to all the women, or that they'd understand his isolation and embarrassment. And he didn't want to intrude on their circle of sisterhood' (*St. Petersburg Times* (USA) 10/20/05).

This 'circle of sisterhood' clearly positions breast cancer as a 'women's disease', a disease diagnosed in women, and a disease women join together for, in fundraising and raising awareness efforts in order to support their 'sisters'. A circle also implies that it is a closed group, that it is constructed of a bond which is hard to break. This positions women diagnosed with breast cancer as a strong, unique entity, and therefore men diagnosed with breast cancer are on the periphery of this 'sisterhood'. In the above quote, Scott does not think that women in a breast cancer support group would understand how embarrassed and isolated he feels. Women may feel isolated from other people in general society, but they are very much central in terms of the breast cancer community, and so there is at least one context in which they can feel included. For men, however, they may feel isolated from both the wider population and the breast cancer population, as they are placed in a position very few people have experienced, let alone understand. The embarrassment may be from Scott having to talk about issues he had never previously considered, but also an embarrassment in terms of making other people embarrassed.

In a similar situation to the man above, Mr Collvins, a man diagnosed with breast cancer, explained how he 'has never met another man with breast cancer, or, for that matter, a woman who wants to talk to him about it' which has made him feel as though he has to go on this breast cancer journey alone (*The Salt Lake Tribune* (USA) 12/13/07). The implication within this sentence is that he has never met a woman with breast cancer who has wanted to talk to *him* about it, but that she would talk to another woman. This reinforces his position of marginality, in terms of the lack of numbers (he has never found another man with the same diagnosis) and also in terms of how other (female) patients view him. His marginality is enforced through the simple low number of men diagnosed with breast cancer, but his marginality is also enforced through his interpretation and understanding of how other people, especially women, now view him. He is aware that women with breast cancer often talk to other women with breast

cancer, and this awareness only makes the lack of women willing to talk to him more obvious. This reinforces his marginality, as he is aware of the groups and resources that exist, and yet other people are not able, or willing, to let him access these. Knowing the high number of women diagnosed with breast cancer each year, he knows there are a lot of people around him who would be in a position to at least share their stories and experiences, even if they did not feel able to give support. But this unwillingness to share their stories with a male patient removes him further away from this group, and leaves him on the margins.

Whilst it cannot be assumed that if there were more services available, more men would come forward to use them, many men who do want to use services are apprehensive about attending places where women are treated (*The Northern Times* (USA) 05/02/08) and as such men are being hampered by the lack of services for men, as well as by their desire to not want to impinge on services used by others. This reinforces the idea that men try to avoid engaging in discussions about their health. Some men, however, do attend female support groups, one such man is Mr Dorst who:

‘now attends monthly meetings for female breast cancer survivors. He was referred to two male breast cancer survivors and has spoken to one on the telephone. That’s not enough help, he says. “I think I get better support from females and from female doctors,” he says. “Still, it would be nice to discuss this with other men.”’ (*Winnipeg Free Press* (Canada) 11/19/00).

This man found it easier than others to access services which are aimed at women, which perhaps is due to his personality, as well as those of the women around him, as previous quotes have shown that some men find it much harder to participate within some all-female groups and services. These women offered something which the men he was put in contact with were not. From a support point of view, this man is able to engage with women in a way which is arguably beneficial to them both, in the sharing of experiences. With regards to the preference for female doctors, there is another element of understanding here. Male breast cancer patients are not part of the majority patient group, but female medical professionals may be able to relate to them in a way which reflects their understanding of breast

cancer and what it means in terms of the role(s) breasts play in their identity. Male doctors may be one step further removed from this again, as this is not an identity they have had to consider before. Marginality is less pronounced here, in the sense that Mr Dorst believes himself to be included in the majority group. He was not able to relate so well to the men in the marginal group, and instead identified predominantly with the women, in a way which the women found acceptable. Similarly, an article about another man, refers to Mr Axline who said that ““Having a support group was very, very important through this whole ordeal”” (*The Columbus Dispatch* (USA) 12/12/04) which emphasises how crucial support groups can be, and groups are possibly doing both men and women a disservice by not fully including men in their activities.

Relating to men participating (or not) in support groups, George, one of the men interviewed for this research suggested that the new website (for the charity through which he agreed to participate)

‘will be more gender neutral but this one is quite pink and um so that’s probably why men don’t most men don’t post directly on to the forums and um also there are quite a few discussions on the forum about um men’s [negative] attitude when um women um are diagnosed with breast cancer [...] I feel it is quite intimidating to read some of it so so that they could be why men don’t post more but we’ve never really encouraged that as well so um it may be something maybe something we can we can think about in the future on the new website’ (George, 11/05/11, p.8)

The use of the term ‘gender neutral’ here refers predominantly to a colour scheme (the presumption being that it will shy away from the pinks and blues associated with females and males) yet also the implication there will be a move away from the overt pink of the website which would be of benefit to its users. Men may feel marginalised by its pinkness, and clear associations with femininity, as well as women who do not see themselves as fitting this stereotyped image of femininity being put off too. The reference to the pink colour scheme of the current website is a strong reflection of how breast cancer is seen as a pink, feminine disease, and the assumption that this is an identity to which the majority of people diagnosed

with breast cancer can relate, or at least are prepared to relate to. Men may indeed be put off from joining and participating if they feel that in some ways they are going to potentially be ostracised more than they already are.

One assumption surrounding ideas of masculinity and femininity is mentioned by Rosalind, a member of staff at the charity who says:

‘but even so you know men don’t for whatever complicated reasons, don’t particularly choose to sort of talk in the way that women do’
(Rosalind, 11/05/11, p. 8)

which is implying that women ‘talk’ in a way that men do not. Whether this is talking in terms of conversations with family and friends, or strangers, there is an assumption that there is an intrinsic nature to women’s talk which allows women to communicate with one another in a way that men cannot. Rosalind acknowledges the reasons for this are ‘complicated’, but does not offer an explanation as to what these might be, just presenting this difference in talk as a fact. Therefore, men are in a marginalised position: as their type of talk is at odds with the way women talk, as women form the majority group the only way men can participate in the breast cancer community is for them to learn to talk in the way that women do.

Rosalind continues:

‘so the sort of support process is quite different there is still a lot of the sort of oh we have to deal with it on your own and the worse thing they can imagine is sitting in support groups whereas for women that seems quite natural it’s sort of extension of female friendships and how they talk you know. So, I think trying to think about how to support men is more complex, it’s not just a case of replicating the service that we successfully run for women, trying to do something for men, but they don’t [want the] same things and it’s hard to know what they do want’ (Rosalind, 11/05/11, p.8)

There is an assumption within this quote that there is a difference between what men and women need. Support groups are defined as an ‘extension of female friendships’ and as such talking in a group seems more natural for

women as that is what they do usually, whereas friendships between men are different, and as such support groups are less of an extension of their day to day behaviours. This relates back to a quote mentioned previously about support groups being a 'circle of sisterhood'. Whilst this is a sweeping generalisation, it assumes both men and women are naturally homogenous groups. A question is to be asked as to why men are seen as more complex. If they do not participate within support groups, why is this, and what services could be provided that they would use and find beneficial? What also needs to be considered when developing resources for men, is that there is a difference between men wanting to be involved, and women not letting them (unintentionally or not) be involved. Men may want the same things as women, but equally women may want their resources to be separate from those for men, so it is not solely a question of providing alternatives. What is already available may indeed be sufficient, but it is its other users who are making it inaccessible.

Negotiating identity

For an individual to negotiate their identity following a breast cancer diagnosis is not a static occurrence, but an on-going and developing transition, with perhaps an unknown outcome. Considering that breast cancer affects individuals differently, there is not 'one' breast cancer identity, but rather an identity which has elements common to many people. A shared identity is developed through aligning oneself with others, for example sharing the same genetic mutation, but men often do not know how to begin this process of aligning with others, due to the paucity of knowledge available. This section explores what is meant by sharing a breast cancer identity, and how men have to fight to become accepted, in comparison with women's usually unquestioning acceptance of other women.

What is a breast cancer identity?

An issue with a 'breast cancer' identity is that there is no such identity that is relevant for all the people who may come under the umbrella label of 'person diagnosed with breast cancer'. Having to negotiate a new identity

can be seen as harder if there is no consensus as to what that identity entails, in order to be accepted by others as someone who has that identity. There is also the consideration of different aspects of an individual's identity, and what will make them seen as a member of a given group. For breast cancer, that consideration is often seen in a split between gender and illness, as emphasis placed on femininity and womanhood may ease entry into the breast cancer community, leading to a shared illness identity, but it is harder to approach this from an illness identity point of view, in which people are seen as patients first, and (wo)men second.

Negotiating identity is not all about how an individual sees themselves, but also how they are perceived by others. One of the forum threads regards a man who is aware he has a BRCA2 mutation, and his searches online about prophylactic mastectomy have led him to the American forum. He asks if anyone has any experiences or opinions to share with him. One reply is from a woman who says she is:

‘so sorry you had to join this group too!’ (*matilda*, USA, 03/07/09)

In this instance, whilst the man in question may not ever be diagnosed with breast cancer, his involvement in a breast cancer forum allows him to be seen by others as a part of this group. When an individual has been diagnosed with an illness, that illness will have been part of them before the diagnosis (for example, a cancerous tumour exists before it is found and identified as being malignant) but it is only through the process of diagnosis that people become to regard themselves, and be regarded, as different. Consequentially, individuals may wish to associate with people who are also aware they have this identity, hence the woman cited above who observes she is part of a group, which the man has realised he is now able to join. As with any named identity, there are going to be inherent ideas and assumptions as to what enacting this identity will entail, and embracing a group identity may have the potential to be stronger than the individuals who comprise it.

The disparity between the ways in which men and women are able to utilise the forum is shown by Michael, one of the men interviewed. He expressed annoyance at women posting for help in the men's thread, and then not

replying when he got in touch with them. There is the possibility here that these women in question were looking for support from other women, about a male relative or friend, rather than seeking advice from a man with breast cancer, but not responding to messages reinforces the marginalisation Michael felt in relation to the forums. This relates back to the notion of sisterhood, that women are in this breast cancer community together, whether they are patients themselves, or carers or friends, and men are secondary to this. Entwined with this is an idea of solidarity, that women are joining together to help support one another, and men are not seen as natural members of this group. Even though, in this situation of exploring what it is like to be a man diagnosed with breast cancer, then arguably talking to a man in that situation would likely be of more use than talking with a woman.

As the internet is a global enterprise, there is more likelihood of men being able to communicate with men in a similar situation. However, this does not mean that it is guaranteed that men will find someone who is experiencing similar situations, such as in the case of Mr Scott who:

‘logged on to some Internet chat rooms and read some blogs. But he never found another man going through the same ordeal. “It would’ve been so much easier if I’d had lung cancer or pancreatic cancer. Those are definitely more socially acceptable,” Scott says. “I’m an aberration that no one wants to know about.”’ (*St. Petersburg Times* (USA) 10/20/05).

The fear expressed here is that breast cancer in men is viewed as abnormal, and therefore something to be feared, which could impact on the extent to which an individual would be able to reconcile this with their identity. Such a view would imply it is difficult to encourage people to be involved in projects related to it as it is such a marginalised experience. Men with cancers only men can develop are ‘socially acceptable’ whereas men with cancer of a ‘feminine’ part of the body are seen as ‘an aberration’. These ideas surrounding conformity to feminine and masculine traits and values will be addressed next.

Men have the same disease, yet a different identity?

One way in which identity can be developed is through aligning oneself with others, and becoming part of the wider breast cancer community and culture: this could be done through the use of support groups. One doctor comments that there cannot always be an appropriate support group for everyone,

‘I think that men’s groups are putting the focus on prevention for much more common diseases such as testicular and prostate cancers, and breast cancer is one of those issues where men really haven’t mobilized.’ (*New York Post* (USA) 02/04/01).

Whilst it may be true that other illnesses and forms of cancer may be better publicised, and also more important in terms of a man’s relative risk of being diagnosed with them, this idea of men not being ‘mobilized’ is possibly one of a lack of opportunity, rather than lack of desire.

‘The lack of options for hiding their disease only leads to more emotional problems for men. Men aren’t sure how to handle their breast cancer diagnosis. With so few support networks and informational literature, there is nowhere for men to turn except women’s support groups.’ (*The Lantern* (USA) 03/07/01).

Faced with a lack of support groups for men with breast cancer in his area, one man named Mr Cowell turned to forums online instead, where he found he was welcomed as soon as the female users realised he was being serious (*The New York Sun* (USA) 04/18/05). The female users of the forum either did not know men could be diagnosed with breast cancer, and therefore thought this man was joking, or they were aware of the disease in men, but did not think men would wish to use a forum and so did not consider his involvement with the forum as a serious behaviour. Whilst it is probable that a new woman joining the forum would be accepted straight away, Mr Cowell had to prove the seriousness of his intentions. It is expected that women will join the forum, as that is appropriate behaviour, but it is not viewed as appropriate for a man, as it is seen as an environment for women. It is doubtful whether a new woman would have been asked to clarify her

diagnosis, or why she wanted to join the forum (except perhaps as a way of finding out more about a person) but Mr Cowell was viewed with suspicion, as why would a man want to join this place for women? He had to prove his intentions were honourable: only then was he welcomed. However, he could only be welcomed as a marginal member of the group, as he lacked the female quality which allowed other people to be welcomed without question.

Paul, one of the men diagnosed with breast cancer interviewed for this research, talks about two other men whom he has encountered on the site:

‘I’m just amazed that in such a national site, only to track so few of us, if there are you know, three hundred a year, and some of us are living for quite a while, that means there are probably a few thousand out there, where are they all? Why aren’t they all on there, you know, communicating, it just seems, perhaps because they’re put off [pause] because they’re not, brought in.’ (Paul, 04/05/11, p.13)

Paul is ‘amazed’ at the low number of men using a national site, as whilst relatively few men are diagnosed each year, logic suggests there are many more men living with breast cancer than one would think at first. There is also amazement that a national charity has not been able to encourage more men into using its forums and support groups. The idea of being ‘brought in’, that men need encouragement in order to begin to participate, places emphasis on the role charities have in incorporating people into the wider breast cancer community. Many people will access this themselves and become immersed with little encouragement needed, but more awareness and guidance may be required by others. Men may need encouragement to participate, and as Park argued assimilation can be slow to occur if the two groups are significantly different. As men are so different from the majority group of women to begin with, their involvement and hopeful assimilation may be slower than perhaps another, more similar, minority group, such as young women with breast cancer. In terms of masculinity, it is a feature of hegemonic masculinity that men do not usually seek help for themselves, especially with it comes to their health. As such, traditionally it has been the role of women to take care of health and well-being, including seeking information. Consequently, it may be beneficial if women in the majority

group can help encourage men to use the forums and resources, to perhaps speed up the process of assimilation and also to protect a degree of hegemonic masculinity enacted by these men.

Paul acknowledges that some websites, whilst overwhelmingly aimed at women, are still good. One in particular, he put a post on the forum:

‘and the first reply I got was ‘hello, I really think you should be putting this in where the men are; and then about twenty minutes later it went ‘terribly sorry, you already have, haven’t you?’ [lots of laughing]’ (Paul, 04/05/11, p.8)

Then later on in the interview,

‘so, that was, you know, you’re not allowed to put er anything on anywhere else on the whole site apart from this little strand where it says ‘for men’. [...] You can’t put [a post] anywhere else, just there. What if I have secondaries? Can’t go up to the secondary bit and put it in there? I’m a man! So, I’m uncomfortable with that’ (Paul, 04/05/11, p.8).

Within these quotes, Paul is explaining how he has been marginalised in a number of ways. In the first, he recalls being asked to put his post on the section of the forum aimed at men, despite this already being the post’s location. The individual who replied saw that it was a post from a man, and felt the best place for the post was on the section for men, despite not checking where the post was. This indicates there is an area for men, and this is the only place where men should post their comments. This is reinforced in the second quote, in which Paul explains how he felt that he was not ‘allowed’ to put a post anywhere else on the forum, despite its relevance. So in his example of secondaries, even if the section of the board for secondary breast cancer would be the most sensible place a question or comment, presuming that the majority of the people reading it will have some experience of secondary breast cancer, because he is a man he is supposed to only post in the section for men, as it is this by which his breast cancer is defined. Even if his question would be likely to get a quicker, better response from a woman posting on the secondary breast cancer board

(especially given that the lack of information on breast cancer in men means that men often undergo the same treatments as women), because he is male he is referred back to a marginalised section of the forum, which gets much less attention and exposure than other areas. He is a 'man with breast cancer' he is not just someone with breast cancer, he has to have his gender incorporated into the label given to his diagnosis.

Again, talking about women using the men's thread on one national charity's website Paul says that:

'you're really looking for the men. To talk to, in the main.' (Paul, 04/05/11, p.12)

Confirming that we are talking about the same thread as mentioned above,

'that's right, yes. Women are, and yet, they don't want you to go on their side of the site, but they want to answer yours haha.' (Paul, 04/05/11, p.12)

There is an idea here that women may not want to include men on 'their side' of the forum, yet they are happy to enter what is named as a thread for men, as though they are trying to exert their presence in this area. On the other hand, Rosalind argues that women often reply to posts from men in order to show support as it may be some time before a man replies:

'you can see women not wanting this person to sort of feel all on their own on the forums. So I think it's done for a you know well-intentioned [reason] and wanting to but I think I think it can yeah there's almost like a sort of mothering role in it [laughs] that is quite interesting.' (Rosalind, 11/05/13, p.14)

This quote highlights how women can be seen as dominating the forum community as a whole. Whilst there may be good intentions behind this, for example acknowledging that it may be a while before a man replies, or they just want to show their support for another person diagnosed with breast cancer, it could be seen as yet another way in which men are marginalised. All the forums had a section for men diagnosed with breast cancer, and yet

men were not usually the dominant participants. Even in an area constructed for them, they are marginal, as it is women who are dominating in this area. This has the potentially negative consequence of putting off men who may wish to participate within the discussions, if they feel that they are going to be secondary to the dominant women in the group, as there is no other place for men to talk solely to other men.

In line with this, when discussing such threads with George, a member of staff at the breast cancer charity, he suggested that:

‘it’s because if you start reading the forums it’s quite, it’s quite intimidating to join a community like that that’s registered and post when you’re new, er and even for women we can see that a lot of them wait a few weeks sometimes months and [then] one day they decide to start posting’. (George, 11/05/11, p.8)

This shows that it can be hard for both women and men to join the forums, and that statistics show many users may wait a while between accessing the site for the first time, and making their first post. The sense of community on the forums is visible for readers and new users may find it hard to start to become a part of that. Individuals may question whether or not they will fit in and if people will approve of their attempts to join in. The fact that some people wait a while between first registering to use the site and actively participating with the forums suggests that there is an idea that there is a certain identity to the group and individuals have to feel able to reflect this in order to feel comfortable enough to comment, and to be perceived as an appropriate participant. Men face a further difficulty here, in that they clearly do not fit the identity shared by the majority of users, and as such may find it a harder area in which to get involved, which in turn further marginalises men as they feel on the outskirts of the majority group.

Referring to the forums, and how people respond to posts, Paul thinks that:

‘what some of that is, is, that there are some volunteers that read all the threads just in case, they don’t want you to post and not get picked up at all’ [as he thinks that] ‘there’s a few folks who their remit is to scan through and if nobody gets a reply in so long you put

a reply on just to say hello really, I think that's kind of what it is really, make you feel you're not completely alone.' (Paul, 12/5/11, p.12)

Such responses to posts may help the original poster in terms of not feeling alone, but if the only reply comes from a member of staff this could further entrench a man's feeling of isolation and marginality as the staff member has felt obliged to reply, due to the lack of replies from other users. This highlights the position of men as being part of the minority group, as it is likely to be very unusual for a post started by a woman not to have a reply. However, the acknowledgement of the staff member does incorporate them into the community in some way, and offers a hand of friendship, although perhaps not as inclusively as men would like.

George, a member of staff at the breast cancer charity, explains that every post made on the forums is read by a member of staff and posts are edited or removed if they are

'not happy with it or needs clinical checking or that's just breached the community guidelines'. (George, 11/05/11, p.7)

Contained within this, there is an obligation, almost, to preserve some element of accuracy, and that becoming a part of this identity is agreeing to this, in a sense. The forum is treated as a service, one which is invested in by the charity. As George continues:

'we've got mostly women on the forum got a few men but um very few have breast cancer, we find that they use the website quite differently if they have breast cancer, so we've got a few partners who visit the site and then post on the forums but not, not, that many we know a lot of them read it but um as far as I know we've got maybe ten users, ten men.' (George, 11/05/11, p.7)

The fact that George suggests there are only around ten men actively using the forums (meaning that they are registered to use the forum, and are not just reading it, for which one does not need to be registered), and that some of these have not received a breast cancer diagnosis themselves shows how

marginalised men are in terms of the breast cancer community. Around 300 men are diagnosed with breast cancer each year in the UK, and taking into account those who have already been diagnosed, this is a large number of potential users of the forum. Admittedly, not all people diagnosed with breast cancer, both men and women, want to use a forum, as shown in the earlier quote from Richard, but even so this does reflect the marginality of men in this particular community as so few of them are active members. This may make it harder for new male members to use the forum, as the presence of women on the site is so dominating.

In line with this, George posits that ‘maybe [male breast cancer patients are] visiting other sites so um or maybe discussion forums [are not] something they’re interested in I don’t know.’ (George, 11/05/11, p.8) It is of course a possibility that the men diagnosed with breast cancer are using other forums, but it does seem unlikely that they are all not using this particular one, which does belong to a leading national breast cancer charity.

When Paul is talking about the number of people who must access the forums each day,

‘have you looked, have you seen how few posts there are from men [...] and how often sometimes the gaps [between posts] can be?’
(Paul, 12/05/11, p.14)

Paul later asks why there is this lack of activity from men, and one possible reason is given by Richard, who said he is not actively using charity forums, although he

‘did look on the forums and I found them quite, some of the threads and discussions [were] obviously quite depressing.’ (Richard, 20/06/11, p.10)

He acknowledges that:

‘there’s, there’s people going through some horrible times [...] I don’t want to be starting down that road for any length of time, I’m a positive thinking person.’ (Richard, 20/06/11, p.10)

Richard finds support from thinking positively, and does not feel the need to use charity forums, although he admits that other people may find them useful. This positive mental attitude, something which other people might find harder to maintain, Richard feels maintains his sense of well-being, and as such does not require the support forums offer, from which other people may benefit. There is an implication within this quote that he finds the posts online to be too depressing, and this is not something he needs or wants to read. He adds that he is in contact through Twitter with a man going through almost parallel treatment, and he is finding some of his support this way. Online forums may be seen as a refuge for some people, knowing there is a place in which they may (eventually) be accepted as part of a community.

How identity management is linked to involvement

The ways in which men incorporate their breast cancer diagnosis into their identity affects their involvement with the breast cancer community, specific charitable events, and the over-arching presence of the pink ribbon. ‘Men’ and ‘women’ cannot be placed together in homogenous groups, but there were differences in terms of how people incorporated their diagnosis into their identity, and their subsequent involvement, or lack of, in specific events as well as supportive endeavours. Involvement is not a prerequisite for managing one’s identity, as individuals may be able to come to terms with it themselves. However, other people may find it hard to talk about their illness, to discuss it and come to terms with it, and so men need to be involved with other men in order to do so. As it is often hard to make contact with another man, men may have the only option of talking with women, yet find that women do not wish to talk with them, as they have the luxury of choice. An organisation solely for men is not seen as effective, and no men expressed a willingness to establish one. In order to incorporate their breast cancer into their identity, men need to decide to what extent they need the support of others to do so, and how they can be seen as individuals within the overarching needs of the dominant group.

Considering women as the dominant group, when Richard in his interview was asked why he thought men did not use forums as much as women, he responded by saying:

‘I think a lot of men are quite obviously quite private and not good at talking about their feelings, I would, I’d probably class me in that category as well but, er, I’d never tweeted before to anybody about anything but I think, um, is what I’ve got a quite interested in increasing awareness amongst men about it.’ (Richard, 20/06/11, p.10)

He says that is it useful to talk to another man on Twitter who is going through roughly the same treatment at roughly the same sort of time and this:

‘is quite useful just comparing symptoms and just checking you’re not [laughs] not got something out of the ordinary going on.’ (Richard, 20/06/11, p.10)

Richard has managed his identity by choosing to not get involved with established forums and ways of communicating, and instead has pro-actively engaged with other men through social networking. What is also highlighted here is the sharing of information, perhaps more so than establishing a connection. Whilst clearly a connection has been made, this is about comparing knowledge and experiences (such as symptoms) whereas perhaps for women a connection would be rooted more firmly in ideas surrounding support. Arguably this is a way of men diagnosed with breast cancer trying to reaffirm an identity concordant with hegemonic masculinity, as they are searching for knowledge rather than seeking emotional support. Richard appears to have not let his diagnosis change who he is, and he has got involved with the breast cancer community in a way which reflects his personality and what he wants to gain from the situation. His agenda seems to be focused on raising awareness rather than solely finding support (as shown in a previous comment explaining how he can find forums depressing) and as such he has incorporated his diagnosis into his identity in his own way.

Paul thinks that:

‘some men are quite, you know, proud in some ways and certain things, and find, find it difficult [to talk about their breast cancer diagnosis]’ (Paul, 12/05/11, p.18)

As such online forums may not be appropriate avenues of support for them, as they might find attending events to be more appropriate. When Paul was asked if he thought face to face support groups would be better for men [than online forums] he replied:

‘yes, for some. Yes, I think for some. Men will always find it easier to talk to other men, rather than women, doesn’t matter to me, I’m easy-going but a lot of men don’t. And there are particular problems that men find it difficult to discuss, problems with tamoxifen, side effects, not everybody wants to discuss it with everybody ha ha.’ (Paul, 12/05/11, p.20)

Asked if he ever went along to a support group, Paul said there were not any, the groups he knew of were for women, and usually for a specific group of women, such as young women with breast cancer, or elderly women. He did not think that there were any support groups that would happily take a man, when asked what he thought would happen if he just turned up he answered:

‘I think it would make the conversation stop. Maybe not, maybe I’d breeze my way through it and they’d be fine with me, but I don’t know, and I don’t really know that I want to. I think I’d quite like to just chat with other men, really [...] It wouldn’t bother me, if it was a mixed group, but I think it would quite bother other people, especially if they were all elderly.’ (Paul, 12/05/11, p.21)

Paul sees himself as a man with breast cancer, and he is aware how this identity could impact upon other people. Whilst it may not bother him, the idea of embarrassment and difference which could be considered by others may lead to their discomfort, and this is the reason he is limiting his involvement.

When Helen, a staff member at the charity, is asked about online forums, she agrees that to an extent they are helpful and beneficial ‘certainly for the female population yes, they are.’ When asked if she thought gender is of influence here, she responds:

‘I think we tried that actually, I’m just trying to think whether it was a telephone support group or an online discussion, live chat, I think we tried it and it failed we only had one man.’ (Helen, 04/05/11, p.10)

She goes on to say that partly this will be due to the small population of men diagnosed with breast cancer, but

‘also maybe it’s a gender issue, erm, I wouldn’t like to comment on that, but that would be what I would imagine.’ (Helen, 04/05/11, p.10)

From this quote, it appears that gender as a specific issue has not necessarily been considered in this context as a barrier to participation, or that it is a situation which arises so infrequently as to be considered perhaps less urgent than others. There is also the idea that staff members do not wish to comment on gender definitions or consequences, reflecting the norms of their social institution in focusing on the majority group, and not being prepared for the possible presence of individuals who fall outside of these specific norms and values. Equally, by maintaining focus on the majority, and not considering other definitions, they may not need to address their own potential weaknesses. These weaknesses can be seen by the marginal man, due to his position: by having a breast cancer diagnosis, a man can utilise breast cancer charities and organisations, their resources and their support, which usually are aimed at women. These marginal men can see how this approach has not given enough thought to the needs of men, as they are unusual. Men will try to be included as much as they can be, but still inhabit a position which is very much on the outside looking in. From this position, they are able to pinpoint the weaknesses within the organisation, and how its norms and values are perpetuated.

Regarding the men's thread on the forum, Rosalind says:

'you'll see you know that it's not used nearly as much as the other threads but it's there, it exists.' (Rosalind, 11/05/11, p.10)

This is displaying an attitude of perhaps we as a charity are doing something, and at least this is better than nothing, especially within the limited resources available, which need to be used to their maximum effectiveness. In the past, she explains telephone support groups were not successful as 'people [men] didn't join', showing here a notion of feeling dispirited about using resources to organise a service which was not utilised enough to make it worthwhile, considering the aims of the charity as a whole. It is a problematic situation in that there probably are men who actively want such services, and would use them, but there are not enough other men to join with them and so make the venture feasible. This is a perennial problem and it is not apparent either from the staff members or the users of the charity themselves what can be done to rectify this.

The forums are, however, a well-utilised resource, and when talking about online forums, Barbara believes that:

'they're very well used, particularly by the sort of under-fifties as you might expect.' (Barbara, 13/05/13, p.9)

There is an issue here that most men diagnosed with breast cancer are statistically likely to be over fifty, and therefore they are not part of a demographic which is very computer literate, judging by the level of the rest of the population. The use of forums does not require an advanced knowledge of computers and the internet, but a degree of competency and confidence is needed. There is scope here that maybe a scheme could be implemented in the near future to support the men of the next generation who are more computer literate, as shown by Richard above and his use of social media.

Barbara talks about people posting on the forums, and how there will be 'lurkers' (so for every individual who posts a comment, there will be several more who are reading them but not actively participating in the discussions

themselves) and how in the threads aimed at men diagnosed with breast cancer many of the posts are authored by women (evident through their username, and content of their message)

‘I mean I’m not surprised the vast majority of posters would be women so I’m not surprised they’re responding to the men cos there probably just aren’t the numbers of men sort of on it every day who would necessarily reply I had, I must admit I haven’t looked at that thread for a long time so I haven’t seen that dynamic erm I mean they are I think a very powerful way of accessing immediate peer support.’ (Barbara, 13/05/13, p.9)

Considering the perceived lack of involvement of men in breast cancer charities, respondents were asked if they thought that perhaps a charity which was for men only would be effective. Paul thought that:

‘it depends, doesn’t it, on all the factors, who did it, how well it’s run, whether it’s got the funding to do it’. (Paul, 12/05/11, p.13)

He would be willing to help out,

‘but I don’t think I’m that keen [to help establish one]. Would take too much time. Want to live’ (Paul, 12/05/11, p.14).

Paul states he wants to live, and his time needs to be concentrated on this, rather than on, in this case, establishing a breast cancer charity specifically for men. He is not overly optimistic as to the hypothetical success of a man-only charity, and as such he does not want to spend time working on such a project. Whilst Paul’s breast cancer is currently in remission, he wants to focus on himself, not on a project which may not work.

He elaborates that:

‘I don’t generally like things to be gender-specific, but, I think there is a need in some cases, particularly in this one, because there are men that are not getting the support they need, that there is to be something more done.’ (Paul, 12/05/11, p.22)

Paul expands that it is difficult to find relevant information and believes:

‘the nurses want it as well, they want to be able to find, and be able to get more support [and whilst there is] a certain degree in common [with women] because cancer’s cancer and all, you’ve got all the issues with side effects of the drugs’ so he concludes that it is ‘probably a good idea on the balance.’ (Paul, 12/05/11, p.22)

He does acknowledge that there are so few men diagnosed with breast cancer so

‘it’s very difficult’ (Paul, 12/05/11, p.23).

In comparison with the men interviewed, staff members were less convinced about the viability of an organisation solely for men diagnosed with breast cancer, or men’s health more generally. Helen explains that:

‘because the number of men is so small it wouldn’t be a viable option but perhaps, thinking about it, a charity, a charitable organisation for men with cancer would be erm, something to think about.’ (Helen, 04/05/11, p.7)

Helen believes the small number of men with breast cancer would make a charity only for them impractical to run, and a charity for men with cancer generally would be preferable. Such a charity though would still position men with breast cancer as marginal, given that the number of men diagnosed with breast cancer a year is small compared with the number of woman diagnosed with breast cancer *and* the number of men diagnosed with any form of cancer. In such a charity, men with breast cancer would still occupy a marginal position, different from their situation currently, but still with potentially negative consequences.

Rosalind was of a similar opinion, in that an organisation solely for men would not be effective. She elaborates,

‘I mean for breast cancer it’s so clearly identified with women that I think men will always be marginal to it and in a way I don’t think that’s the end of the world, I sort of think we’ve got to concentrate our effort on women’. (Rosalind, 11/05/13, p.15)

This remark is truthful in that as women are the majority of people diagnosed with breast cancer, it seems fair that the majority of resources are allocated to them, and this is something the men interviewed have commented upon as well. George thought that a charity focusing on men as cancer patients would not be effective because:

‘you obviously want to deliver to as many to as many [people] as you can but at the same time to do that you need to raise money and by excluding um a group you reduce your income so I would say um I wouldn’t see why a charity would want to do that’. (George, 11/05/11, p.5)

Helen concludes that:

‘I feel I’m absolutely passionate about the needs of men but, you know, I just think, yeah, we’ve done as much as we can do, without having a whole male breast cancer charity being set up’ (Helen, 04/05/11, p.9)

which she has already said is not currently a viable option. Within these arguments put forward it is queried as to whether any minority group is going to be able to have an ideal quantity and quality of charity support, due simply to the restraints in terms of, for example, available funding, and a lack of medical knowledge. This may be something which cannot be altered solely by individuals or charities, and perhaps needs addressing from a multi-agency body, to incorporate other possible avenues of support to produce and support a more holistic approach.

The impact of a breast cancer diagnosis on men is not something well-known, and Rosalind suggests:

‘we don’t want to talk about that really, about you know about the impact that breast cancer has on men [...] breast cancer still has a massive impact on men’s lives, but we don’t really find a way to talk about that.’ (Rosalind, 11/05/13, p.8)

This is an area which needs investigation, if aims of gender equality within cancer organisations and the people who use them are to be reached. Barbara explains recently the charity has put together an approach towards equality and diversity which is enabling the organisation to think about gender more openly throughout its services and operations. Helen thinks that it is:

‘an on-going issue that we all need to be aware of’ (Helen, 04/05/11, p.9)

and although this may be occurring there are held concerns that this focus on gender equality is not strong enough. Michael fears that men:

‘still get pushed on [the] side [meaning that breast cancer] will always be a women’s problem, I’m afraid’ (Michael, 07/05/11, p.20)

He later suggests that:

‘you look at the Kylie Minogues, who are heroes aren’t they, and the Karen Keatings, who were put on a pedestal, and go how brave they are, well aren’t I as brave as them? I went through it’ (Michael, 07/05/11, p.25).

The way this man speaks sounds as though he thinks he is not asking for a lot, and maybe is disheartened by charities and their activities. He suggests that a possible reason for charities not doing what he thinks they could do, and are capable of, is due to a (lack of) funding. Rosalind suggests that what makes the charity for which she works unique is that:

‘we’re the ones doing something for people who have got breast cancer now’ (11/05/13, p.17)

but the issue here will be to ensure that they are the ones doing something for as many people diagnosed with breast cancer as possible, although admittedly there is the obligation to focus on what can be reasonably achieved.

Conclusion

It is apparent that men and women diagnosed with breast cancer have different experiences in terms of participating within the breast cancer community, due to a number of factors. Ideas of masculinity and femininity are seen and interpreted by both men and women in different ways, and how these can influence the extent to which individuals wish to become involved, as well as the extent to which their involvement is accepted by others.

There is often a split between gender and illness, with focus being placed on one, rather than the other, or a combination of them both. Focusing on gender identity means women are easily able to access the breast cancer community, as the emphasis the breast cancer community places on ideals of femininity and womanhood are visibly portrayed. It is much harder for men to access such a community, as for them the ideals are lacking. This reinforces how Bury's concept of biographical disruption is not appropriate for exploring the experiences of men diagnosed with breast cancer, because the difficulty involved in trying to access the wider community shows men do not automatically have the knowledge available to redevelop their identity. It also shows the appropriateness of using a marginal man framework, as men have a double membership, and from their privileged position they are able to see the standards that are in part used to exclude them.

Approaching this from an illness identity point of view, in which people are seen as patients first and (wo)men second, would be much harder: there is not the information about breast cancer in men that there is for women. As shown through the work of Star, the standards of the breast cancer community as a whole are too rigid to successfully include the deviant case of men with breast cancer. The standards have produced exclusions, and

even if illness identity was seen as the focus, the breast cancer community would struggle to incorporate this fully, given the restrictions it has created and developed.

Negotiating identity is an on-going and evolving process, and involves a balance between one's illness identity and their gender identity. Although men and women with breast cancer share a common illness identity, if their gender identity is viewed as dominant then the fact that they share this illness identity may be seen as secondary, meaning men maintain a marginalised position on the outskirts of the community. If it is femininity and ideals of womanhood which unite people within this community, then gender identity does have an important role, and men may have to learn to accept this in order to be satisfied with their participation. If they are willing to accept the overarching pink nature of the breast cancer community and its associated institutions and organisations, they may be better placed in order to participate. It is their place within the pink ribbon culture which is the focus of the next chapter, exploring what is understood by the culture of the pink ribbon, how there are gendered identities within the associated pink ribbon campaigns, and what the gendered assumptions of behaviour stemming from these gendered identities are, within the context of these campaigns. This will build on the issues surrounding identity explored in these first two empirical chapters, to develop a comprehensive idea of how men experience being breast cancer patients.

Chapter Six

How men diagnosed with breast cancer fit (or not) in the pink ribbon culture

Introduction

Breast cancer, and its associated pink ribbon, is a global illness, and one which is viewed universally as a disease associated with women. The annual breast cancer awareness month in October, with its displays of pink (from bathing internationally-recognised buildings in pink light, to the selling of novelty pink items) positions breast cancer as a female illness. With 30,000 women diagnosed with the disease each year in the United Kingdom, it is a disease which in many respects dominates the charity landscape. There are however a smaller number of men (around 300) each year who are diagnosed. As such, these men are able to view the pink ribbon culture in a way which is unique to them. They are at the same time part of the community, through a shared diagnosis, and yet remain on the edge of it as their masculinity and their experiences mark them out as different from the majority within this community. This is a privileged position, as it gives them a double vision. These men are experiencing the marginal position and at the same time viewing what is occurring with the majority group. These men are able to see differences in the ways in which events and situations are structured and potential ways in which slight differences could be made. It is this social positioning which provides a unique vantage point.

As with arguably most groups, there is a diversity in terms of how men with breast cancer view the pink ribbon and its associated culture, and this diversity contains contradictions in how the pink ribbon is both valued as a tool for raising valuable awareness and research funds, and yet contains within it the potential to alienate not just men, but also women who perhaps do not fit with the pink stereotype the pink ribbon portrays. Referring back to the work of Sulik (2011), the pink ribbon has achieved many good things for the breast cancer community as a whole, but there is potential for detrimental situations to occur as a result of the culture and branding as a whole. The culture of the pink ribbon goes beyond just the buying and

wearing of a physical pink ribbon, and extends to the purchasing of novelty pink items (such as dyed pink food items) as well as to purchasing standard products, but with a percentage of the sale going towards breast cancer organisations. There are concerns over where the money is going, will it benefit all people with breast cancer, whatever their identity? There is the risk that it could be detrimental if people are put off by perhaps the overt femininity of the products, or perhaps the unnaturalness of some items, such as the dyed food items.

The pink ribbon, the only ribbon colour to be associated with just one health condition, in its pinkification positions itself at a certain point in society and has the potential to ostracise people who do not conform to the norms it entails. This is reflected through the use of particular identities within pink ribbon campaigns, and how this leads to stereotyping of people within the campaigns. The pink ribbon campaign has arguably transformed breast cancer from a serious social problem into a popular item to be publicly consumed. It encourages people to be positive and upbeat about breast cancer, rather than acknowledging how different and difficult the reality might be.

Alongside this is the idea of stereotyping, the idea of a warrior, and that people who buy a pink ribbon product are buying into this identity. There is not the space for people diagnosed with breast cancer to be seen by the public as having a different identity, and if people do not fit this identity then they may feel they are not publicly considered to be meeting the perception of what a person with breast cancer should be like. This may negatively impact upon men diagnosed with breast cancer, and also women who are uncomfortable with the views it supports and portrays. By focussing on the privileged point of view occupied by men with this illness, the pink ribbon culture and its associations can be seen from both an insider and an outsider point of view.

Diversity and contradictions in men's view of the pink ribbon culture

All the interview respondents were asked for their views on the use of pink within charity campaigns and whether, for the men, this had had any bearing

on their involvement at any point. Paul declared that the use of the colour pink did not bother him at all, and Michael opined that he had:

‘no problem with pink, pink’s just a colour, just a mixture of red and white, and colours don’t bother me,’ (Michael, 07/05/11, p.19).

He just wanted there to be a way in which men could be mentioned and incorporated within this. Any issues are not with the colour itself, but with the connotations implied through the use of this colour in campaigns. A colour does not have intrinsic meaning, but meanings are applied to it through its use in society: individuals and their social interactions infer meanings on to particular colours, and their uses and appropriateness. Regarding the use of the pink ribbon at official events, Paul indicated towards a pink hat he would be wearing at an upcoming event and declared

‘I’m sort of out and proud, you know’ (Paul, 12/05/11, p.16)

and that he would be wearing this pink hat as an accessory to his t-shirt which says ‘survivor’. Whereas Michael saw pink as nothing more than a blend of colours, admittedly a blend he saw as omitting men, for Paul the colour has more meaning, as he embraces its connotations of survivorship and will wear the colour with pride. Paul’s use of the phrase being ‘out and proud’, a phrase associated with gay people making their sexuality publicly known, implies that he is happy for people to know of his diagnosis, and he has embraced this and accepted who he now is.

This idea of being ‘out and proud’, of people being happy for their diagnosis to be known is important for this research, as it links with the involvement of men within breast cancer charities and organisations. All the men interviewed for this research were recruited through a breast cancer charity, and all were happy for their diagnosis to be publicly known. Clearly, it is not simply a gender split, implying women are bound to become involved with such organisations, and men are not, as the personality of the individual, as well as their gender, may well impact upon their level of involvement. The three men interviewed all reflected often vastly different levels of engagement. Paul, who was diagnosed with cancer, has been involved with charities ever since he was first diagnosed and continues to

play an active part in local and national events. Richard wrote about being diagnosed with breast cancer on Twitter and a national charity sent him a message, and whilst he himself has not used any of their services,

‘I did read something about the research and thought I’d happily help out in any way I can really’ (Richard, 20/06/11, p.3).

There is a possibility that the age of men diagnosed with breast cancer potentially becomes a barrier to involvement as Paul suggests some men are:

‘from a different era, when they didn’t talk about these things, and some men may find it a little shaming because of the gender issue. It’s not a man thing, you know [...] I think particularly because it’s seen as a female disease.’ (Paul, 12/05/11, p.17)

Considering that men are often diagnosed with cancer when they are quite old, they may belong to a generation which is less communicative about breast cancer, and wider health issues, in men which could impact on their involvement.

Paul thought breast cancer charities focused on women:

‘because that’s the vast majority of people [who are diagnosed with breast cancer]’ (Paul, 12/05/11, p.14).

This is a clear acknowledgement that the focus of charities is on the majority group. Michael argued that, with reference to men (not) getting involved with charities, women are better able to make themselves heard because:

‘they [charities] listen to ‘em [...] they’ve got a better voice to listen to’ (Michael, 07/05/11, p.26).

This idea of a ‘better voice’ is descriptive in a number of ways. Women dominate the breast cancer community in terms of numbers of people, and so by speaking together, their collective voice is loud in volume and

therefore easier to hear and listen to. Because women are the majority group in terms of breast cancer, it is likely that simply in terms of numbers, the views of some women are likely to be replicated for other women, simply as there are so many of them. Dominant features of the breast cancer community, for example the use of the colour pink, and events organised by women for women, may reflect a symbolism which is shared by the majority of women within the breast cancer community. However, women are not a homogenous group, in the same way that men are not a homogenous group, so charities are only able to hear the group which is shouting loudest. Men, being a small group within the breast cancer community, are separated from this shouting group. This positioning gives them a privilege, in that their position enables them to see how this majority group is behaving.

In terms of his mastectomy, Richard argued that:

‘for me as a man losing my breast isn’t really I don’t see it as a major problem cos it doesn’t do much and you can’t tell it’s gone really’
(Richard, 20/06/11, p. 6)

Perhaps because of this, it is only accurate that the majority of literature be aimed at women. Whilst some of the literature he was given was, for him, unnecessary, such as ‘reading all the side effects [of Tamoxifen], you know about vaginal dryness’ (20/06/11, p.6) he says that the female-focus of the literature ‘doesn’t bother me at all’ although he ‘can’t speak for anybody else’ (both Richard, 20/06/11, p.7). Here, Richard is setting himself as being apart from the majority of breast cancer patients who have mastectomies. By declaring that for him such an operation would not be a ‘major problem’ there is the implication that for other people (namely women) it would be.

Here, Richard is setting himself as being apart from the majority of breast cancer patients who have mastectomies: by declaring that for him it was not a ‘major problem’ there is the implication that for other people (namely women) it would be. A detachment from the idea of having breasts originally may mean that their removal is seen as less of a loss, as their presence was not noted earlier.

Paul was of a similar opinion with regards to his mastectomy, saying that

‘the operation itself is not really, for a man it’s not a big deal [of] trouble, although it’s a full mastectomy you can hardly tell the difference to be honest, apart from I don’t have a nipple anymore.’
(Paul, 12/05/11, p. 2)

In a sense, although a mastectomy is a serious medical procedure, regardless of the sex of the patient, the consequences, specifically psychological consequences, of such an operation could be fewer for men than women. Rosalind, a member of staff at a breast cancer charity, surmises that:

‘the impact on their [women’s] lives is far more devastating [than men’s] so I don’t sort of feel we should apologise for not you know we’ve got limited resources and therefore you know our priorities have got to be women.’ (Rosalind, 11/05/13, p.21)

This is a valid point, in that limited resources do need to be utilised in a way which benefits the most people, however to say that a breast cancer diagnosis will affect people of one gender more than another is quite possibly a step too far and is also a generalisation. It is arguable that whilst impacts on lives are going to differ from person to person, this cannot be generalised to specific genders. A diagnosis of any form of cancer will impact to an extent on patients’ lives, due to the severity of the disease. There is the potential for such a belief about different levels of impact to unintentionally pervade further, which could have bearing upon wider services.

It is clear that breast cancer organisations are focused on women, as they form the significant majority group diagnosed with the disease. Whilst this does potentially include the risk of alienation for men, there is the knowledge that breast cancer is a relatively common disease and as Richard suggests ‘you know the systems are in place for it,’ and that therefore ‘the fact that the literature isn’t totally focussed in men is an issue you have to live with’ and that he would:

‘rather the money was spent on, you know, treating people and increasing awareness than er focussing or spending thousands of pounds on literature for just cos a few hundred men a year get it compared to fifty thousand women I think that’s silly [seeing] how the literature can double up.’ (Richard, 20/06/11, p.7)

This is a valid statement in that much of the literature can ‘double up’ and that as with all charitable endeavours, funding is limited. Also, as so few men are diagnosed with breast cancer, there is a general lack of clinical knowledge surrounding the disease, so some of the information available for women (such as side effects of drugs) is genuinely unknown for men. This lack of knowledge is remarked upon by Helen who argues that as a charity they try to use words which are gender-neutral but:

‘the problem is always going to be that most research is just relating to women and it has to be applied to men which is potentially problematic and that from the clinical perspective I think that men are probably as covered as they can be.’ (Helen, 04/05/11, p.6)

There must not be a danger that the lack of men-specific information be used to justify the lack of focus on men.

Clearly the pink ribbon is one of the key images associated with breast cancer, and whilst this is usually viewed as positive thing, George, a member of staff at a breast cancer charity, is the only respondent who suggests a potential negative connotation. The colour pink, so strongly associated with breast cancer, could be a reminder to patient users of their medical situation, when perhaps they wish to utilise charity services as a location of friendship and support, to move the focus away from their illness. However, George concedes that the ‘corporate partners like it and that works for fundraising so it’s a dilemma that we’ve got.’ His views may be different from others because of his work position and how he personally has not had breast cancer. There is the acknowledgement that the pink ribbon, and the wider range of pink products available, has been incredibly successful in terms of its association with breast cancer, and its strong identity makes it a popular choice for businesses in terms of supporting a charity. This means that it would be incredibly hard to alter any element of

the pink ribbon, as this could be detrimental to fundraising efforts, and links with corporate clients.

The culture of the pink ribbon

One of the dominant parts of the breast cancer charity calendar is national Breast Cancer Awareness Month (BCAM), which occurs every October. A pink ribbon is the symbol of breast cancer awareness and is used in many contexts and on many objects. The pink ribbon has both fans and critics, as well as the connotations of pink, femininity, and the ramifications of this upon the diagnosis and treatment of men with breast cancer.

One article provides a concise overview of the pink ribbon, which

‘is the symbol for breast cancer awareness and was invented in 1991 by Evelyn H Lauder, founder and President of the Breast Cancer Research Foundation, and Alexandra Penney, then editor of *Self* magazine. Lauder says, “The ribbon stands for awareness.” It also stands for the sisterhood that will help women to survive – and conquer – this disease. Pink Ribbon Pakistan has been addressing breast cancer issues since 2003 with its nationwide breast cancer awareness campaign, its aim is to make this cruel disease a premier health concern. Pink Ribbon Pakistan is dedicated to fighting breast cancer at every stage.’ (*Daily Times* (Pakistan) 11/09/10).

In America, this idea of the pink ribbon joining and uniting people is expressed with reference to Susan G. Komen’s Race for the Cure,

‘Thirty thousand pairs of sneakers. Thirty thousand pink ribbons. Thirty thousand people trying to beat something’ (*The Baltimore Sun* (USA) 10/19/09)

which reflects how people are being mobilised through the pink ribbon and associated events to raise awareness. However, the quote from the first article fails to explain how this ‘sisterhood’ will help men. Within this quote, men have been ignored, and the focus is solely on women helping

women. Men here are not seen as a minority group, they are not even acknowledged.

The enduring symbol of breast cancer awareness is the pink ribbon, and alongside this, during breast cancer awareness month every October, there are many pink products on sale with a percentage of proceeds being donated to breast cancer organisations. Pink has very feminine connotations (despite it being, in the 18th and 19th centuries, a colour associated with little boys rather than little girls) and in turn this further entrenches into public perception the idea that breast cancer is a women's disease, supported by women for women. The pink ribbon, and more generally the 'pinkness' of breast cancer awareness campaigns, was the focus of a number of forum threads, further showing how identity work within breast cancer communities is female-orientated.

One user on a British forum commented that

'after watching a tv programme tonight I was surprised at how little men's breast cancer was published and as women have pink ribbons I was wondering if a blue ribbon could be done for men.' (*lionness70*, British2, 07/03/10)

Due to the perceived lack of a blue ribbon for men, in order to engage with breast cancer awareness, both men and women have to engage with the established pink ribbon. With the strong link of pink with heteronormative femininity, this involves gender identity work, in order to fully engage with the community. In order to be seen by others to be members of this community, men need to show the emblem of breast cancer, which is the pink ribbon. Here it is their illness identity which is linking them with women, they are sharing the breast cancer ribbon, which just happens to embody feminine ideals, thus removing the focus from men being *male* breast cancer patients. This reflects the marginality of men, in that they cannot fully be accepted into this community as there will be an aspect to their identity which distinguishes them from the majority. The absence of a ribbon specifically for them – as this poster shows, 'women have pink ribbons', shows men are to many extents excluded. Even if, as the poster suggests, a blue ribbon was commonplace for men, they would still remain a

marginalised group, and would still have to engage with feminine gender work in order to attempt to become part of the majority group.

On the American forum there is a thread with a link to a BBC news story, where a man with breast cancer suggests the pink ribbon could have a blue stripe or dot to represent the men affected. One woman responds,

‘I think his idea about a pink ribbon with a blue strip or dot makes so much sense! How else will public awareness about the potential for MALE breast cancer happen unless the public is faced with the prospect on a regular basis – that breast cancer CAN hit a man as well as a woman...the blue mark brings our focus back to that!
(*Lauren6*, USA, 05/11/11)

Having a blue marker of some description on an otherwise pink ribbon, to be used throughout breast cancer awareness programmes, would allow for attention to be given to the fact that men are diagnosed as well as women. With this poster commenting that a blue mark could bring ‘our focus back to’ men being diagnosed, this shows how men have had to become part of the all-female element, and attempt to join with the pink priority. By bringing the focus ‘back’ to men, this would allow men to be seen as admittedly a marginal group, but a marginal group which still deserves its own recognition.

The next person to respond includes the website of an American foundation set up for male breast cancer, which uses and sells a pink ribbon that fades to blue in one leg. This shows how allowances have to be made for men, that they are not considered to be automatically included.

One man on the American site asks for people’s thoughts about pink ribbons in general. He says:

‘I am really torn. Up until I was diagnosed, I would see something pink and buy it for my wife. Now, after reading posts on here, and my experiences, I have come to the realization that I do not know how I feel about the pink ribbon anymore. On one hand, all of the publicity has helped many different research orgs get money.

However, it seems to me that if they would have pushed male BC awareness with the same power, I would not have been misdiagnosed for 8 years. I feel a little burned by that.’ (*Peter10*, USA, 13/09/11)

This man is arguing that the pink ribbon culture has emphasised the risk of women having breast cancer to such an extent that medical professionals were unable to correctly identify his illness for many years. If breast cancer in men was as well known as breast cancer in women is, this may not have happened as more people would have been aware of the probability of the diagnosis. As such, the pink ribbon can be seen as having a detrimental effect on men’s health, an effect which could be life-threatening.

A woman responds,

‘As for the whole pink-tober party, it kind of freaks me out. The supermarket is the worst in October...YIKES...pink bagels! It’s kind of an embarrassment and really trivializes what we go through...especially at Stage IV. I mean come on, could they show a little class? There needs to be a balance between raising awareness and money, and respecting those who already have a diagnosis’ (*steelrose*, USA, 13/09/11)

It is accepted that there needs to be a campaign to raise awareness and funds, but this needs to be offset against the seriousness of the disease. In this example, pink bagels are seen as exaggerated and trivialize the seriousness of the illness, as beside from the pink colour, there is little to link bagels with breast cancer. Even if a percentage of the cost of the bagels is going towards a breast cancer organisation, the relatively small amount could further trivialize the disease, and move the focus away from people who are suffering from it.

Another woman responds with a similar remark,

‘I also didn’t realize until recently that many women with BC have mixed feelings about the pink ribbon stuff. I was kind of glad to see that, because I have always felt that a lot of it trivializes and makes “cutesy” what is a very serious, frequently fatal, disease. But I guess

it does help with raising funds for research etc' (*Daydream*, USA, 13/09/11)

What is contained within this post are notions of what constitutes 'good' and 'bad' within breast cancer awareness. The less desirable elements can be seen as items which may trivialise the breast cancer mission, such as turning common foodstuffs pink. However, the purchasing of such items 'does help with raising funds' and as such may outweigh the 'trivial' intrinsic nature of the product. The acknowledgement that these items do raise money and awareness is something that needs to be considered as a positive alongside the potential negative feelings created by these products. Equally, the pink ribbon is not something which solely alienates men, as shown by the above quote many women also have reservations about its domination. Whilst it may be evident that men do not fit in with the pink ribbon culture, it may equally becoming apparent that neither do all women.

Another replier to this thread says:

'pink pens, donuts, visors? I just cannot stomach it. Many groups use pink simply to increase profits. And as a cancer patient, I never found any useful info or actual support from anything pink. In some ways, I feel that it distracts from the severity by making pink all too common. I don't have a solution, or a better idea, I just know that pink is revolting to me now, and I refuse to purchase anything resembling it. I'd rather make direct donations to groups I know which truly help women directly' (*abcabc*, USA, 15/09/11)

Despite the fact that the original poster is male, and wants to raise awareness of breast cancer in men, the responder above appears to omit men from the group of people they would like to help. The OP responds that he is 'happy to hear that I am not alone in my feelings.' Another man agrees with what has been said before,

I think the whole pink ribbon campaign is good, as it does raise awareness and money. But I agree with some, that as a male I find it kind of trivializes the disease and makes it "cute" (*Mnomno*, USA, 21/09/11)

As a man, this poster is within the marginal group of this context and as such he has the vantage point of being able to see what is possibly overlooked by those who form the majority. Consequently, he sees how the pink ribbon risks trivialising a serious illness, something which the majority of people do not, or at least do not draw attention to it. Men may already feel that their masculine identity has been damaged by being diagnosed with breast cancer, and therefore work needs to go into this to ensure he is still seen by others as masculine. To engage with such a 'cute' pink ribbon is to threaten this masculine strength. If the pink campaigns were structured so as to be less 'cute' and to respect the potential severity of the disease, this would allow men to become more involved and less marginal as they would not have to feel the inherent strength of their identity to be under threat.

Why pink? The issue of pinkification

Pink has always been the colour associated with breast cancer, and indeed the pink ribbon is the only coloured ribbon to be affiliated with only one disease or health condition. There are concerns, though, about the overuse of pink in products aimed at women, and more broadly in terms of what pink connotes. For example, the campaign Pink Stinks targets products and company marketing that prescribe roles to girls and young women which are stereotyped and arguably limiting. This issue of 'pinkification' is especially valid in terms of breast cancer, as the relationship between the illness and the pink coloured ribbon and associated products is so strong and enduring. Whilst Pink Stinks investigates how the colour can negatively impact upon girls, in terms of breast cancer 'pinkification' the focus is on its impact upon men, and also the women who do fit the pink stereotype.

When asked about how she thought organisations consider gender with regard to breast cancer, Rosalind, a member of staff at a breast cancer charity, replied:

'I think it's a difficult one in breast cancer because you know out of fifty thousand cases of breast cancer that are diagnosed in the UK a tiny minority are men [...] like five hundred or something, so it's

seen as a very female thing, the vast majority of people who work here are women, and the vast majority of people who use our services are women, and it's very pink you know, the whole breast cancer is very pink.' (Rosalind, 11/05/13, p.7)

Breast cancer has been firmly established as the illness supported by the pink ribbon, and it would be incredibly difficult to separate the two, even if that was desirable. Breast cancer has also been established as a disease mainly affecting women, and a disease supported by women, as shown through the number of patients, and the employees of this particular charity.

George concurs with the female, pink aspect of breast cancer, and believes that:

'we still haven't found the right way of doing global fundraising without alienating part of the audience, [...] women who don't like pink and fluffy.' (George, 11/05/11, p.9)

The 'pink fluffiness is quite a barrier' concedes Rosalind, and imagines that men 'would go on our website and sort of get information that way without having to talk to anybody.' An assumption held within this comment appears to be that men prefer an individual, silent, approach to their involvement with breast cancer, and perhaps see charities more as sources of advice, which is in contrast to what the men interviewed here thought, as they saw the main roles of charities as being that of support, followed by advice. It is this dichotomy which needs addressing. Potentially there is a situation in which men are not informing charities of what support they need, and as such charities are not providing that support because they are not aware that men are seeking it. Barbara thinks that sometimes they as an organisation 'forgot what it might be like to be part of or try to be part of what is seen probably as quite a feminised organisation.' She goes on to say:

'as I said I think there's a sort of slight default towards thinking about women erm rather than thinking about men because that's obviously overwhelmingly the number of people affected.' (Barbara, 13/05/13, p.4)

However, she does acknowledge that:

‘we have had to think and rightly so about what that means for the sort of three four hundred men diagnosed each year and [...] you know there have been some men who have sort of pointed out to us that they’ve felt the whole thing is too pink and that you know that’s quite alienating.’ (Barbara, 13/05/13, p.4)

There is the acceptance here that the breast cancer field as a whole has potentially made an already difficult situation for men harder. Not only do they have to come to terms with their new identity as a breast cancer patient, and the threat this illness poses to their health and potentially their life, but they must also decide on the extent to which they are happy to try to involve themselves within the community, and embrace its norms and values, embodied so universally by the pink ribbon.

Barbara continues, and says that this has:

‘led to some interesting discussions at times about on the one hand we can’t change everything for a very small number on the other hand we don’t want to make their experience worse and make them feel like we don’t also have services available for them.’ (Barbara, 13/05/11, p.4)

She is all too aware about the dangers involved if they ‘pander too much to stereotypes’ (13/05/11, p.5) as they need to acknowledge the impact breast cancer has on both men and women, and whilst they would like to be of help to everybody who needs that help, realistically such a goal is unlikely to be achieved.

The emphasis on the colour pink and pastel shades can be seen as a ‘culture shock’, as described by patient Mr Brooke, who said he was generally the only man present and “‘I was sure all the women in the breast-care center thought I was supporting my wife’” (*Houston Chronicle* (USA) 06/12/03). With the focus being on women, and how such an environment may make men uncomfortable, Mr Goldstein, who was diagnosed with breast cancer,

makes the valid point that men do not really discuss male-specific diseases such as prostate cancer, and therefore find it even more problematic to embrace this female environment and talk about a 'female' disease such as breast cancer (*The San Diego Union-Tribune* (USA) 06/22/03).

The debate around the colour(s) of the breast cancer ribbon is raised again in an article reporting on the American Race for the Cure and how each year the event:

'creates rivers of bobbing pink T-shirts and hats in cities throughout the country, as hundreds of thousands of breast cancer survivors and their supporters run or walk 5 kilometers [sic] to fight the disease (*The New York Sun* (USA) 04/18/05).

Mr Kramer, who has breast cancer, wants there to be 'a few flashes of blue in those groups' to help overcome men's ignorance of breast cancer –the combination of pink and blue would establish a visual representation of how breast cancer affects both men and women. The article explains how 'The Komen Foundation [organisers of Race for the Cure] has begun to roll out gray [sic] T-shirts for the race...but it has been hesitant to adopt blue because the color [sic] is associated with prostate cancer'. Whilst an entirely blue ribbon may well indeed be associated with prostate cancer, this does not fully explain why a pink ribbon which included a blue thread could not be used for breast cancer, without detracting from prostate cancer awareness campaigns. Mr Kramer is on a 'quest for gender equity' as the utilisation of an all-pink ribbon is arguably discriminating against men, and preventing them from realising there is a risk they could develop the illness too. Mr Cowell, another man with breast cancer, builds on this argument, and explains that the dominance of pink is not what bothers him, it is the overall lack of education and publicity, with men being added almost as an afterthought when publications state that men can develop it as well.

A similar viewpoint is held by Mr Scott who is 'tired of reading stories about the march for the cure...sick of the sisterhood of support' (*St. Petersburg Times* (USA) 10/20/05). Whilst he understands more than most people what they have endured, he is 'forgotten' when the literature for a disease which is 'really common' rarely considers how it has the potential to

affect other men like him. He felt he would have to try and raise awareness himself, a view also held by other men with the disease who 'say there is no help or resources for them and they suffer in silence [...] If you need information, you have to hunt for it' (*Herald-Sun* (Australia) 07/15/09). What appears to be at issue here is the disparity between the levels of awareness of breast cancer in women and in men. Whilst no one is suggesting that awareness of breast cancer in men should surpass that of women, this balance does need to be readdressed so that men are not as isolated as they currently see themselves as being. This also relates to the development and utilisation of support groups.

The concept of the pink ribbon has grown to include a wide range of pink products which are representative of the breast cancer campaign. One lady is:

'encouraging people across the country to use *Pink Power* to help beat the disease. Whether they wear a pink ribbon button hole, pink clothing to work, hold pink coffee mornings, or even a pink cocktail party, every bit helps' (*Grimsby Evening Telegraph*, 09/19/01, emphasis added).

Putting 'Pink Power' in capital letters gives it an authority and dominating strength, something which people can harness in order to help beat breast cancer. It is not clear however, how wearing pink clothing to work as suggested can help beat a serious illness. If there is a monetary donation to a charity or organisation then the link is logical, but the colour pink itself does not hold a special power to beat illness.

The range of pink products also has been extended to include men (although this area is still growing and is lacking awareness in some areas): 'Look at that GUY in the pink shirt! With the pink cap! Hmmm, must be for his wife. Or maybe his mother. But you look closer, this man is wearing the pink symbols for himself.' Later on in the article, Mr Goldstein says "'I never felt for one moment that this was an assault on my masculinity. Some men are so preoccupied with macho endeavors [sic] that they panic at the thought of getting a 'woman's disease'. It just wasn't an issue for me'." (*Evansville Courier and Press* (USA) 09/14/00). This shows how that pink

ribbon concept has developed, and needs to continue to develop; men are willing to wear pink products for the affected women in their lives, but also for themselves. Whilst the focus is still, and is likely to remain, on women, it is widening slightly to be more accommodating for men, especially as men begin to embrace it more for themselves. What is also important to remember is that 'Just as women and men pin pink ribbons to their chests as a sign of support and vigilance, breast cancer survivors, too, are a shining symbol of hope' (*The Arizona Daily Star* (USA) 09/30/01) and that whilst the ribbons are indicative of hope, so are the women and men who have survived a breast cancer diagnosis, thus providing hope and inspiration for those unfortunate to be diagnosed in the future.

However, whilst the pink ribbon has been embraced, for many it is too 'pink' in its design which has spread to include many other products, services, and events. Whilst not wanting to detract from what it has achieved, and what it can do in the future,

'Now, just as female breast cancer advocates banded together to help publicize the disease among women 20 years ago, a disparate group of male survivors, including...actor Richard Roundtree...are working together to put what one calls "a touch of blue" in the pink ribbon given to those who have beaten the disease' (*Toronto Star* (Canada) 08/09/02).

A 'touch of blue' implies a small presence, one which is there yet not overpowering, allowing the work of the pink ribbon to continue almost undisturbed, but allowing men to have their presence acknowledged.

The colour pink is so commonly associated with femininity that this may be ostracizing to men and potentially damaging to any campaigns attempting to raise public awareness of breast cancer in men. As shown in the previous quote, there is an argument that the pink ribbon should be altered slightly: by incorporating an element of blue (the colour most commonly associated with masculinity) this will immediately indicate that breast cancer is something which affects men as well. The relevance of this is shown by Mr Lowe who 'never met another man with the same disease. All the literature he was given was coloured pink and written for women' (*The Hamilton*

Spectator (Canada) 04/12/03) and

‘For men with the disease, it’s like *swimming against a tide of pink*. Oceans of ink have been dedicated to raising awareness of breast cancer. It has gone from a topic not talked about among polite company a generation ago to one of the most-discussed health issues of all time.’ The lack of publicity about breast cancer in men reinforces the notion that breast cancer is a woman’s disease and men need only worry about their wives, daughters, mothers and sisters.’ (*The Hamilton Spectator* (Canada) 04/12/03, italics added).

‘Swimming against a tide of pink’ shows the strength of the pink ribbon, and how it is almost unstoppable in its dedicating to breast cancer and its dominance in health social movement campaigns. Charting its history shows a social force which has grown and changed the lives of many. This emphasises the point that whilst it is accepted that the pink ribbon campaign has had many accomplishments with regards to breast cancer in women, this same level of achievement needs to be aimed for with regards to breast cancer in men, yet maintaining a fine balance in terms of not detracting from the work and effort women have put into the pink ribbon campaign, and what it has already achieved.

The pink ribbon does have its critics, though, and one is Derek Wright: if he:

‘had his way, pink ribbons and purple bras would be scrapped as the symbols for the cancer that threatened his life. He believes these feminine symbols help perpetuate a potentially harmful misbelief that men are immune to breast cancer’ (*The West Australian* (Australia) 06/25/08).

When asked if he owned any pink objects, Mr Quick replied that he did not, something which does not make him any less of a survivor of breast cancer (*The Augusta Chronicle* (USA) 10/31/08). The idea that an affiliation with pink products is almost an obligation for people affected by breast cancer is one which may be detrimental to public awareness campaigns, and also for people who do not wish to associate with such a feminine idealisation; this

could include individual women, as well as men. In his discussion of his breast cancer experiences, Mr Thomas described himself as:

‘a blue bloke in a pink world – the drugs are in pink boxes, the consulting rooms are pink, I even have a small pink enamel ribbon that I wear to pharmaceutical conferences. For now, I’ve only one request: wouldn’t it be brilliant if men were made a little more aware and that the breast cancer symbol of pink ribbon might be given a thread of blue running through it?’ (*The Mail on Sunday*, 01/04/09).

This idea of a blue thread would reflect the minority aspect of the number of men diagnosed in comparison with women, whilst not detracting from the work women have done in the past, and continue to do, to support cancer care organisations.

This idea of a dual-coloured ribbon is not new: an article from 2000 (nine years before the above suggestion) reports how the John W. Nick Foundation created a pink and blue ribbon ‘but few have ever seen it’ (*Esquire* (USA) 06/01/00). The article focuses on Dave and Teresa Lyons who launched a breast cancer in men support group in their area as they ‘felt so alone in their struggle’. They acknowledged that it is through the actions of women breast cancer has such a prolific public profile today, and as such ‘they have every right to own it [the fight against breast cancer]. Just not entirely.’ Teresa explains how women told her they did not want men in their groups, or participating in events, as it is ‘a woman thing’, even though the man here has experienced the same illness as themselves, and is not trying to detract from their experiences, merely take support from them and perhaps try to be of support to others. The couple explain how participating in a Race for the Cure event impacted negatively upon them, and how they felt as though they ‘didn’t even want to turn in the money’. If people are willing to support a fundraising campaign, but feel their support is either unwelcome, or unnecessary, this could have a detrimental impact on future involvement and fundraising generally, as individuals may spend their limited time and resources on other initiatives.

Gendered identities in the pink ribbon campaigns

The majority of events organised under the umbrella of the pink ribbon are accessible for all people, and men, women and children are encouraged to participate whether that be through attending events, buying pink products, or supporting those who do. As such, men can and do participate, but, as this section will argue, in a way which has associations with femininity, such as modelling in a fashion show, and purchasing and wearing pink items. There is the assumption that men will not be able to fit in if they try to be different, as indeed they begin from a marginalised position. To try to change the ways in which men participate is seen as hard, and accompanies an argument that perhaps it should not be changed, as that could undermine all the work the pink ribbon campaign has done already.

The pink ribbon culture focuses on fundraising and awareness activities and events which are generally quite ‘feminine’ in their content, and as such portray woman in a specific way. In the newspaper articles there were a number of events mentioned which showed men participating in ‘feminine’ activities. Mr Mayes, a man diagnosed with breast cancer, is participating in a fundraising charity fashion show (*Scottish Daily Record*, 09/30/05) and he is keen to raise awareness about breast cancer in men (*Sunday Mail*, 10/02/05 and 10/01/06). A fashion show was also mentioned, which had male breast cancer survivors, in *Nottingham Evening Post* (09/27/06), and it was ‘Robert Kerr [who] got the loudest roar’ at a charity fashion show (*Sunday Mail*, 09/30/07). In a similar ‘fashion’ sense, Mr Hall, another man diagnosed with the illness, is collecting bras to hang along a street to raise money for a local hospital, as well as trying to raise awareness (*The Journal*, 04/22/04) and

‘The second annual High Heel-a-thon is on September 26, with proceeds going to Yorkshire Cancer Research. Participants must start and finish the 1.5 mile city centre fun run in the heels, though they are allowed to take them off for most of the course. Clair Chadwick, head of marketing and fundraising at Yorkshire Cancer Research, said: “This sponsored fundraising is a vital initiative to help us raise awareness of both male and female breast cancer”’ (*Yorkshire Evening Post*, 06/25/10).

These articles are of interest in that men are using them to raise awareness of their illness in the public, their illness in terms of how breast cancer needs to move away from being seen as a disease with which only women can be diagnosed, but in a way which is so resolutely associated with femininity. Whilst men do participate in the fashion industry, bras are an item of clothing only designed for women and as such it seems almost counter-productive to try to raise awareness of a disease in men using clothing only worn by women. Admittedly, the association between bras and breast cancer is apparent, but much less so the association between bras, breast cancer, and men. If a member of the public were to see this initiative, it is possible that they would not consider men as breast cancer patients, and it would need explaining to them. This means that the awareness element of the campaign is not apparent, as campaigns should not have to be explained to their viewers. One article reports how John Spansel and his late wife, who both had breast cancer, were honoured with an award to recognise their efforts to increase awareness surrounding women's health issues (*Times-Picayune* (USA) 07/22/07). Although the article does not go into details as to what their efforts consisted, it seems odd that they have been awarded for their work on women's health issues, when both the couple have been diagnosed with the same disease, therefore one which clearly affects both sexes. Even if perhaps their work focused on screening programmes, for example, it seems remiss that breast cancer in men is not more explicitly mentioned. Another article reports on a brunch for cancer survivors organised by the American Cancer Society, during which a man who had had breast cancer was nominated for an award for community involvement in helping others with cancer (*Times-Picayune* (USA) 03/13/05). Again, men with breast cancer are in the public domain, and yet specific awareness work is perhaps not as effective as it needs to be.

There were a few articles about charities and attempts to specifically raise awareness of breast cancer in men. Mr Steele explained in *Scottish Daily Record* (06/27/08) how he started contacting cancer charities as he wanted a resource for men with breast cancer to be produced. He said he did not like the disease being referred to as male breast cancer, as women are not referred to as having female breast cancer. This is firmly positioning men as being part of the marginal group.

Mr Avery, the youngest man to be diagnosed with breast cancer in the UK, has held a charity night to raise money for a number of breast cancer charities, and he also took part in a charity fashion show (*Echo*, 10/29/08). Mr Cleckner is a survivor of breast cancer and participated in the Making Strides against Breast Cancer fundraising walk and there were t-shirts which said 'real men wear pink' (*Akron Beacon Journal* (USA) 10/11/09). Sixty bikers went on a bike ride to raise awareness of the disease, one of them was a male survivor of breast cancer (*The Morning Bulletin* (Australia) 10/26/09/). This 'real men wear pink' slogan is implying that wearing pink will not negatively affect a man being perceived as masculine, and it may actually reinforce their masculinity as they can be seen to be above and beyond gender stereotypes. The campaigns involving pink do have certain feminine connotations, perhaps of support, caring, nurture, other traits usually seen as belonging to women, but men can embrace these as well, without fearing that it will damage how other people view them as men.

When asked in their interviews what they thought of the pink ribbon, there were many references to breast cancer campaigns and their connotations, both positive and potentially detrimental. The pink ribbon 'is such a well-known trademark of breast cancer' says Richard (20/06/11, p.12) that he 'wouldn't change it' as this potentially could be detrimental to avenues of income and people who wish to become involved. As he surmises,

'men are the minority, and shouldn't be banging their drum too much, I think maybe on some of the fundraisers I would like to do the walk the Moonwalk next year and I'll go along and wear my pink ribbon and [...] I'd highlight the fact that you know I am a sufferer and you know I'll do that with pride and it won't bother me at all but I think the pink ribbon should stay cos it is it targets the right sector of society which is ladies and should in my mind.' (Richard, 20/06/11, p.12)

This strong idea of men diagnosed with breast cancer 'banging their drum' is one which is potentially damaging to the breast cancer cause. He is arguing here that the pink ribbon, and what it represents (namely, that of women who have been diagnosed with a disease strongly associated with

femininity), has a purpose in that it links the group that it represents with those who potentially feel the greatest affinity to it. Women may choose to identify with the pink ribbon breast cancer cause because of its strong female history, and its strong ties with women today (some events for breast cancer charities are female-only), and the risk associated with such an identity is that if the identity is altered in any way, this could potentially be detrimental to the way in which it is supported. Referring to the pink ribbon, and the general pinkness of breast cancer awareness, Barbara thinks that it has:

‘been brilliant in terms of galvanising a public consciousness and understanding of breast cancer [and] does set up an interesting public image that we then have the choices about how to deal with that and what nuances we make within that.’ (Barbara, 13/03/11, p.10)

The pink ribbon has been an enormous success for breast cancer awareness, and nothing should detract from this. A public image has been set up, and as it has been so successful there is an argument for not changing that, and possibly risk damaging its good work. However, as the public acceptance of it may be changing, or if it is no longer seen as the most appropriate way of symbolising breast cancer, then this does need addressing and consideration made towards how it could be changed, altered or interpreted.

Alongside this idea that breast cancer organisations are strongly associated with women, Rosalind suggests that there are other stereotypes and preconceived ideas surround breast cancer, and as such it is not just men who may feel isolated.

‘I think there is a sense of breast cancer being seen as quite a sort of you know WI [Women’s Institute], twin set and pearls you know, it’s sort of women it affects, which of course it’s not like that because older women are all sorts of people.’ (Rosalind, 11/05/11, p.22)

If such a perception is held by members of the public, almost regardless of its (in)accuracy, issues can be raised about who has the confidence and perhaps social capital to be willing and able to access such an area. The pink ribbon, whilst aiming to involve everyone is raising awareness of

breast cancer, may have the potential to alienate members of the public through misconceptions.

Although 'lots of men get involved in our fundraising events' it is not necessarily 'in the way that women do,' suggests Rosalind. She furthers her suggestion by admitting:

'we're a very pink organisation [...] do men want to run the London marathon in the pink t-shirts, I'm not saying that there's anything wrong with that or that they shouldn't, but it wouldn't appeal to a certain group of men.' (Rosalind, 11/05/11, p.12)

It can be seen as acceptable to assume that different events, for whatever their purpose, are going to appeal to different people, due to differences and individualities. However, it is perhaps unfair to say it would not appeal to a specific group of men without exploring why. Regarding the men interviewed for this research, one is embarking upon a national breast cancer charity event along with three male friends, and another said he publically wore pink survivor clothing items with pride. Such attitudes and assumptions and the 'type' of people who are likely to attend a certain 'type' of event are potentially alienating not just men, but other demographic groups, which could be detrimental on a range of levels, from individual well-being to involvement on a wider scale.

The charity has in the past tried organising and running services solely for men 'but the uptake hasn't been very high' admits Barbara which is:

'not surprising because you're talking about a very small number of people so to reach them properly is quite complicated.' (Barbara, 13/05/11, p.5)

Whilst charities are organising services and events for men, these need to be publicised; as there are so few men diagnosed each year it may be harder for information to reach everyone. Here there is also the reliance on breast cancer nurses actually knowing about the services so that these nurses can act as a bridge between medical services and charitable ones. Focusing on men, Barbara explains that as a charity they try to ensure they have men

who are willing to be contacted by the media so if ever there is media interest in men diagnosed with breast cancer they are able to be put in touch.

Advancements in technology, and the growth of new social media, have presented different opportunities for people to become involved with charities. George acknowledges that the charity for which he works has specific publications for men and that:

‘it’s technically nowadays easier for us to tailor information that’s for patients’ (George, 11/05/11, p.4).

Alongside this the charity is trying to move towards making publications gender neutral because:

‘when we’re talking about supporting partners, we’re aware partners aren’t just men’ (George, 11/05/11, p.5).

In this way, the charity is involving men as partners of women diagnosed with breast cancer, but clearly there needs to be an emphasis also on men diagnosed as patients themselves. Equally,

‘I would say we’re trying to be more gender neutral than doing something specifically for men’ posits George (11/05/11, p.5)

but it is not clear whether this is the most appropriate route. Whilst admittedly literature and information which is gender neutral is arguably accessible to more people, as discussed previously, pieces of information have different levels of relevance when applied to specific groups, and as such it would perhaps be better to have a specific focus, rather than one which is broader in its scope. Breast cancer patients are not a homogenous group, in the way that all men diagnosed with breast cancer are different, as are all women, and as such they as individuals may be searching for something different from the charity.

Within the forums for men with breast cancer, there is often the assumption held within people’s comments that women will be reading what is written.

One wife in the US site posts on behalf of her husband who currently has side effects from treatment:

Ladies, I know you all chuckle and say now men know what we go through but it's not his fault or choice. We're just having a bad day.
(*Paula1970*, USA, 05/07/11).

No actual question is presented in this post, and a reply comes from a woman who writes:

'It is bad enough having cancer, let alone cancer that mainly affects women. Our emotions can be so raw at this time and it must be difficult to be the butt of jokes when you are asking for help'
(*Beachy*, USA, 06/07/11)

There is an assumption here that a breast cancer diagnosis will be worse for a man than for women, although the men interviewed for this research as a whole thought breast cancer was worse for women. A man, who identifies as a 'breast cancer survivor/thriver', replies:

some of us 2000 men/year who get breast cancer [in the US] just seem to deal with it silently – and that's OK if that's your choice. I find it helpful to participate in some discussions as it lets me get it out instead of holding it all in. And possibly I can help someone.
(*MarkJon*, USA, 06/07/11)

In terms of gendered identities, there is an assumption that men will not fit into the majority group, as they stand out as being different. A key assumption is that men will be the 'butt of jokes' for having a cancer which mainly affects women. Breast cancer in men is seen as not to be taken seriously, and something which can be made fun of. This assumption from the beginning positions men in a marginal position as they are already deemed to be less serious than women in their diagnosis. It is acknowledged as being 'bad enough' having cancer, and that it must be worse to have a cancer mainly affecting women. From the offset, breast cancer is seen as belonging to women, and men are bound to find their

experiences worse as they have the double impact of a serious disease, and the negative consequences of being the ‘wrong’ gender for this disease.

In the quote above, this man acknowledges that all people diagnosed with breast cancer are individuals, and as such both men and women are likely to behave differently when it comes to engaging (or not) with contexts outside of their medical treatment. This poster, through stating why he is involved in forum, shows that being able to participate in discussions allows him to ‘get it out’ rather than ‘holding it all in’, something which he views as beneficial. By using the idea of choice, he states it is okay not to be involved, as long as the individual has made that choice by going through their options: it is not okay if the individual has ‘chosen’ not to get involved because this was in fact the only option available to them. This idea of ‘holding it all in’ here has implied negative consequences, so people who are not provided with the opportunities, and the choice to get involved, are at risk of not being able to ‘get it out’. This man self-identifies as a ‘thrivor’ of breast cancer, no doubt helped by finding an activity which he has been able to define as ‘helpful’. This is a route to surviving and thriving that could be of use to other individuals, if they had the opportunity to choose.

Gendered assumptions of behaviour stemming from gendered identities in the pink ribbon campaigns

Gender is relevant more broadly with regards to cancer, and in a thread in a British forum there is a link to a newspaper article from the Daily Mail (entitled ‘*Men are most at risk because the NHS prefers saving women, says cancer expert*’) which suggests a divide in the NHS with differences in gender statistics. The article presents statistics for a number of cancers (not breast) from which men are significantly more likely than woman to die. One man starts a thread on this, posts a link to the article and then writes:

‘Yes, I will hold my hand up and admit that when it comes to listening to our own bodies, admitting that we need help and visiting our doctors is something that we blokes are pretty **** at. And it is, by and large, the most obvious explanation for the difference in detection and survival rates. But surely, this should be ringing serious alarm bells both with the NHS and CRUK. But instead, more

and more men are dying from cancers that are both preventable in many cases and easily cured if detected early' (*Bobo1955*, British2, 21/09/11)

Immediately there is an assumption that all men are not good at admitting when they ought to go and see their doctor about a possible symptom. By using the pronoun 'we' the original poster is writing as though he is speaking on behalf of all men, and the gendered assumptions that come from this are being applied to all men, when this is not necessarily true.

He goes on to suggest that:

'Knowledge is, as they say, power. And knowledge is key in the battle against cancer so what I believe is needed is a major education campaign aimed directly at men which should be spread across all media outlets: TV adverts, newspaper/magazine advert, radio and of course, online. We men do take notice of these things eventually and the more of us that take notice, the more lives can be saved. Also key to the campaign would be to really hammer home the message to men that seeing your doctor as soon as you notice something abnormal is not in some way admitting defeat or should be something to be embarrassed about' (*Bobo1975*, British2, 21/09/11)

Whilst there has yet to be the type and size of campaign suggested by this poster, campaigns aiming to raise awareness of cancer in men have been running to some extent, and men perhaps should have therefore noticed by now. Raising awareness is essential, but what is also a necessity is getting people to act upon this knowledge if necessary. As such he also suggests that there is a need to 'really hammer home the message to men that seeing your doctor as soon as you notice something abnormal is not in some way admitting defeat or should be something to be embarrassed about.' He suggests that it is time to move the focus from women to men in order to try to close this survival gap. Is there a way, however, of helping both women and men simultaneously? He sometimes feels 'as though we [men] are second class citizens when it comes to research and prevention of cancer'. Within these comments is a feeling of exclusion, that men are, in a number of ways, being omitted from breast cancer communities. The cancer

statistics highlighted in this post indicate that more men are dying from cancer than women, and that significant work needs to be done to address this. With the respondent here commenting that both the NHS and CRUK need to address this, he is highlighting the element of exclusion as these organisations have, it appears, yet to acknowledge the disparity between the two sexes.

The first reply to this is male and agrees that:

‘blokes are blokes and will probably only go to the doc when nagged by ‘‘er indoors’ or when something is so bad it warrants looking at. Until men change their attitude towards this, nothing will change’ (yesaman, British2, 19/06/08)

The implication here is that ‘real’ men do not willingly visit a medical professional of their own accord, and instead only visit to appease their female partner. Therefore, even if there is increased awareness and knowledge, men still will need persuading to see a doctor, as to willingly visit would be to invite potential criticism of their masculine identity. This idea is supported by someone who believes:

‘men **do** know when they need to see their GP it’s just that sometime they refuse, point blank, to go!’ (*Spinning*, British2, 19/04/10, original emphasis).

Perhaps men are aware of health conditions but not the severity of them. The author continues that perhaps everyone needs reminding to see a doctor, and that perhaps:

‘women don’t go either – because they’re busy working, juggling children, shopping, cooking’ (*Spinning*, British2, 19/04/10)

and that it is not just a gender-specific phenomenon, giving an example of female acquaintances who do not get regular cervical smear tests. The post is finished with a succinct comment that:

‘I feel that both men and women need to be told it’s okay to ask for help and most importantly to expect to **get** that help once you ask’ (*Spinning*, British2, 19/04/10, original emphasis).

Only one person comments that some men just ‘prefer to stick their heads in the sand and hope for the best.’

In one of the British forums, a man explains how he is going to a cancer conference later in the year and asks if there are people who would like to share their experiences of cancer from a male perspective.

Us blokes are supposed to be strong, self-reliant and brave. Are we really like that – or do we just get to be that way by ignoring the things that threaten us for as long as we can? At any rate, the vulnerability that comes with serious illness can be a huge challenge to our sense of ourselves as men [...] no-one would dispute that men find it harder to ask for emotional support (*ABYZ*, British3, 20/09/06)

This post is questioning how experiences of cancer can depend upon one’s gender and how this is perceived. Whilst men are viewed as ‘strong’ and ‘brave’, this is not necessarily an accurate description in a breast cancer context. Men diagnosed are aware of these adjectives used to describe men, and so to avoid showing how affected they have been by their diagnosis they can accentuate how they portray these adjectives, in an attempt to show their masculine identity has not been altered through ill health. By this poster questioning if men are really as strong as they want to be seen, this reflects a desire on behalf of men to fulfil what is seen as a masculine ideal. If all men are aiming for these ideals daily, then men diagnosed with a disease associated with women have to go beyond this in order for their identity as strong men not to be threatened. As this man later suggests, serious illness can challenge how men see themselves, as illness targets directly the concepts of being ‘strong’ and ‘self-reliant’: physical strength can be sapped through cancer treatment, and this may lead to increased dependence on others, at least for the duration of treatment. This challenge needs to be overcome if the man is to continue to be seen as a man, by himself and others. Strength can be viewed in other terms, for example being a support to other people, as seen via those who participate within

these forums. Bravery is shown by these individuals making their diagnosis public and doing what they can to raise awareness in others. These actions can help reinforce a masculine identity which has previously been under threat.

Regarding the point of view that ‘no-one would dispute that men find it harder to ask for emotional support’, this reflects the notions expressed above that men need to be strong and self-reliant, and therefore to ask for emotional support is to work against these characters of masculinity. In reference to the OP, the first response (from a woman) thinks this is a good idea, mentioning the names of two men (who presumably are active members of the forum) and tells them that this is their opportunity. A woman responds asking if women:

‘can tell the story of how ‘our’ men coped’ or does it need to come from them directly?’ (*sweetie*, British3, 20/09/06)

This shows that women are active users of the forum and are often posting on behalf of the men in their lives. This takes it a step further and indicates that women are often used to or required to speak on behalf of their male relatives in both the off- and on-line worlds. The OP responds to this message saying whilst he hopes that there will be some men willing to write about themselves, he would also be pleased if people wanted to talk on behalf of their men. There is a need here to ensure that the experiences of men are put into the public domain. The OP would like men to do so, as this could provide encouragement for other men to share their experiences also.

Conclusion

There are obvious differences in how men view the pink ribbon culture, ranging from an admiring acceptance of it and fully embracing the colour, through to an indifference to its appropriateness for men, through to feelings of its inadequacy in terms of fully showing the public the reality for men diagnosed with the illness.

It is not just men who have divergent feelings towards the pink ribbon, and the 'pinkification' of the social movement as a whole. The forums were often used by women and men to express dismay at how everyday products were being turned pink in order to raise awareness and funds, but in a way which risked trivialising the seriousness of the illness. Gendered assumptions surrounding the colour pink influenced to a degree the extent to which individuals felt they could become involved in its campaigns, in a way which reflected the delicate balance between their illness identity and their gender identity.

The pink ribbon campaign has achieved a great deal since its inception, and the extent of this cannot be underestimated, but there is a need alongside this to respect its heritage and continue its growth in a way which is better able to encompass more of the people affected by a breast cancer diagnosis. One key area on which the pink ribbon focuses is the raising of awareness of breast cancer, and this is the focus of the next chapter.

Chapter Seven

How awareness and lack of awareness are linked to hegemonic femininity, and reinforce hegemonic masculinity

Introduction

The previous chapters have explored how breast cancer can challenge hegemonic masculinity, how men negotiate their identity in the wider breast cancer community, and how these men fit (or not) into the pink ribbon culture. This chapter focuses on (the lack of) awareness, and how this is linked to hegemonic femininity, and reinforces hegemonic masculinity. Hegemonic masculinity in Western culture can be seen as having qualities such as physical strength, emotional restraint, an ability to provide for and support others, and a daring, risk-taking attitude towards danger. There is also the presence of power, both over other subordinate forms of masculinity as well as over women. Hegemonic femininity is less well-defined, but can embody a caring and nurturing personality, of being emotionally weak, and less strong than men.

The awareness of breast cancer in women and the lack of awareness of breast cancer in men are linked to these ideas of hegemonic masculinity and hegemonic femininity. Awareness does not exist in and of itself, it is constructed through the social interactions of individuals, and the institutions in which they reside, specifically the institutions of health care and charity sectors. In terms of the health care institutions, a lack of awareness can run throughout specific areas of the institution, from staff through to users, which can impact upon the type and quality of information and care given and received. The lack of screenings available for men places them in a position from which they need to be proactive, as they do not have this to rely upon. Charities are likely to have their own individual aims and objectives, implying their awareness campaigns are likely to be focused on achieving these. By providing an additional service to those provided by public services, the great number of charities in existence may mean that people do not know what is available to them. Therefore, there is

the possibility that certain gender identities are demonstrated and represented.

Many of the articles focused on men who either have, or have had, a breast cancer diagnosis, and how their experiences have inspired them to try and raise awareness in, and for, others. An analysis of these articles explores the idea that as a minority group, men diagnosed with breast cancer have almost an obligation to raise general awareness. This obligation can be related to concepts of being strong and protecting others, qualities associated with heteronormative masculinity, and as such can be in line with spreading knowledge of breast cancer in men.

How awareness is constructed by institutions of the health care and charity sectors

As previous chapters have shown, awareness needs to be developed and raised, and this is not done in a value-free environment. Through their work and campaigns, health care institutions and the charity sector are trying to disseminate knowledge and raise awareness about a specific disease, and the specific ways in which that disease is viewed. This is done in a number of ways, for example through the literature produced, and the type of events organised, as well as for example restrictions on the people eligible to take parts in events (for example, Cancer Research UK's Race for Life is for women and children only). In combination, these can illuminate how men experience being breast cancer patients.

How the health care sector constructs awareness

Previous chapters have shown the general lack of awareness about breast cancer in men, but this is not limited to the general public, as shown by Mr Whatmough talking about his diagnosis:

‘It was a bit of a shock. I had never heard of men getting breast cancer. I have a wife who is medically qualified and she hadn't either’ (*The Herald*, 09/05/02).

Whilst it does not say to what extent his wife is ‘medically qualified’, it does indicate learning about breast cancer has focused on women, and as such ignores the disease in men. This is apparent in other areas of the medical environment:

‘That must be why the woman on the phone laughed. She was in a doctor’s office. Bryan was calling for an appointment. He said he had breast cancer. She chuckled. “I could see why” he says. “People don’t think of men as getting it”. Men, especially.’
(*Greensboro News and Record* (USA) 05/29/05).

Despite the professional, non-judgemental nature assumed to be a prerequisite for working in a medical centre, this man with breast cancer when arranging an appointment was assumed to be joking. Whilst he understands that people do not think of men having breast cancer, such a reaction is unprofessional and reflects the positioning of breast cancer as a disease of women. There is an idea that women as well as men need to be more aware of breast cancer in men. Clearly, men need to be aware as it is their body, but if women are aware then they can be of use to the men they know in ensuring that men visit their doctor if necessary. Such an idea reinforces hegemonic masculinity, by placing women as care-givers looking after the health of others, and visiting medical professionals when deemed necessary, as well as showing men to be less aware of risks to their health. Mr Hackbart, who was diagnosed with the disease:

‘had no idea that males could get breast cancer. That never entered [his] mind’ (*The Capital Times* (USA) 06/02/00).

Mr Parry, another patient, had:

‘the unexpected news that he had breast cancer’ and believed that because breast cancer is rarely diagnosed in men ‘most men don’t worry about breast cancer’ (*Deseret News* (USA) 06/09/00).

These quotes show that even if men are aware of their breast cancer risk there is the attitude that it will not happen to them, that serious illness only affects other people.

One way in which awareness of breast cancer in men can be raised is through medical professionals and researchers. A nurse-educator says:

“We just really need to have it mentioned out there. We need men to be more visible with breast cancer. Men need to know this exists and they should be checking for lumps”.’ (*Winnipeg Free Press* (Canada) 11/19/00)

Similarly, an oncologist argues men do not think that it could ever happen to them, but it is still important that people are aware of it (*The News-Gazette* (USA) 07/21/01). However, these articles do not actually explain how men are to become more visible. It is acknowledged in many articles that awareness needs to be raised, but it is less often suggested how this goal may actually be achieved. A similar message is displayed by a researcher arguing it is:

“important to make males realize [sic] that it can happen and that they need to watch out for signs and symptoms because they don’t get screened” (*The Windsor Star* (USA) 12/11/09).

As men do not participate in regular screening programmes like women do in many countries, they need to be vigilant, as it may be up to them to detect a problem with their breast health, whereas for women this could first be noticed through a mammogram. This reliance on men’s willingness to engage with medical issues and their health may be at odds with ideas of hegemonic masculinity, as the focus is on men being pro-active about their health, and assumes men have prior knowledge.

A final article suggests:

‘A new group of people should consider getting tested for genes that raise the risk of breast cancer: men. Male relatives of women with such genes often do not realize [sic] that they, too, may carry them, and face greater odd of developing male breast cancer, as well as prostate, pancreatic and skin cancer, new research suggests’ (*St Louis Post-Dispatch* (USA) 01/14/08).

There is clearly a desire for more people to be aware of breast cancer in men, but it remains unclear who should be leading these campaigns and how they should be best structured in order to have the biggest impact. These quotes show people within health care sectors are conscious of the need to raise awareness of breast cancer in men, and yet there is less focus on how this can be achieved. As such, the lack of action results in continuing the main agenda of focusing on breast cancer in women, restricting men's access to the wider breast cancer community, and maintaining their marginal position.

How the charity sector constructs awareness

Many cancer and breast cancer-specific charities developed from health care organisations, or have a current focus on a medical research into the disease. This results in an overlap between how the health care and charity sector construct awareness.

With a medical background, Helen, a member of staff at a breast cancer charity, sees the role of cancer organisations and charities as being:

‘an adjunct to the services that are provided either in the social care or the public service so NHS, erm, private sector healthcare, it's like, from our charity point of view we're about information and support and [other charities] are about research erm, so you know, everyone will have their particular area of erm, expertise that they do well.’
(Helen, 04/05/11, p.5)

By positioning charities as an additional service to ones offered by public services, there is likely to be similarity in how awareness about breast cancer in men is constructed. Helen mentions charities have their own individual focus and aims and objectives, but under an umbrella term.

When Rosalind, who works at the same charity, was asked about what she thinks the role of cancer organisations and charities generally are, she replied:

‘I think what we hope to do is support breast cancer nurses in sort of you know giving people information and support, I also think voluntary agencies can work as more sort of political lobbying, they can have that sort of role which is harder for the NHS, so, you know I think what we hope to do is support, inform, and influence, that’s what we talk about doing, so we hope to influence sort of you know government agenda breast cancer and stuff.’ (Rosalind, 11/05/11, p.5)

Rosalind acknowledges the restrictions placed on the NHS in terms of what it is able to achieve given its necessary priorities. Charities are able to position themselves in a way which can build upon the work of the NHS, and develop this further, such as through political lobbying as suggested. She hopes they are able to be influential. As such, charities are perhaps best placed to increase awareness of breast cancer in men as this may be beyond the capabilities of the NHS. However, as above, there is not information as to how to progress from here.

As shown, charities are encompassing a range of provisions to support those diagnosed with breast cancer as well as the people caring for them, in both professional and personal capacities. Helen suggests that due to the sheer number of breast cancer charities operating in the United Kingdom, it could be:

‘quite confusing for people out there to know who does what, to try to message things properly’ (Helen, 04/05/11, p.5).

Both Helen and Rosalind see charities as occupying a position from which they are able to attempt to influence key decision-makers, but there are not specifics presented as to how this might be accomplished. The quantity of cancer and breast cancer charities in existence, although they all have their own aims and objectives, may mean the public does not know of all the options available to them. There may need to be more cohesion in campaigns in order for a specific message, in this case raising awareness of breast cancer in men, to be portrayed and perceived. Without such cohesion, the position charities are in may just reproduce what is already

present, with a focus on women and continuing to view men as the marginal majority.

Due in part to this awareness of breast cancer being positioned as a women's disease, for many men diagnosed with breast cancer, this comes as a surprise diagnosis. For instance, George Reis:

'thought himself pretty aware of breast cancer, its issues and its effects. He'd seen the pink ribbons. He had female relatives who'd had the disease' but he still did not think when he found a lump that it could be breast cancer (*The Knoxville News-Sentinel* (USA) 10/15/01).

There is the possibility here that he was indeed 'pretty aware' of breast cancer in women, because the usual focus of breast cancer awareness campaigns is women, and that is the knowledge he had. If men had a bigger part in such campaigns, then perhaps the message would get through. This quote clearly shows that awareness campaigns do work, as the public is aware about breast cancer, and that as such, if minority groups were included the public would be aware of these too. It is important to know that men can be diagnosed with breast cancer, but it is also important that men know what specific symptoms to look out for.

It was not just members of the general public who seemed surprised that men were involved in their world. Mr Minnards, who has breast cancer, said of his situation:

'some cancer care organisations surprised me by their attitude. I'd ask for information and it would arrive addressed to Mrs Minnards. At the breast cancer outpatients clinic the receptionist insisted I'd come to the wrong place. I already felt uncomfortable being the lone man among the other female patients in this clinic. My advice to other men is not to assume it couldn't happen to you' (*The Sunday Mirror*, 09/17/00).

Mr Minnards already felt uncomfortable due to his diagnosis, and how this now placed him in situations in which he was the only man outnumbered by

women. These feelings were compounded by the fact that he was seen as an error, and that his title had to be wrong, a typographical error, as only women are perceived as able to have breast cancer, and so rather than check if the title was an error, the person who posted out information changed his title on correspondence. Cancer care organisations should be aware of who can be affected by certain diseases, and there is also the possibility of a man enquiring about breast cancer on behalf of a female friend or relative, and to alter the title is a gross assumption. Then later for a receptionist in a medical environment to assume, without checking, that Mr Minnard was in the wrong place, added to his feelings of isolation. This strongly shows the dominance of women in this area, and how men are being marginalised. The work of Star (1991) argues for an understanding of marginality which is not based solely on people – in this quote the man is not seen as ‘wrong’ in terms of who he is as an individual but because he is male, and this is the exception to the norm. Standards produce exclusions, and as such this man is between worlds, trying to access the breast cancer community but being denied because he is the ‘wrong’ gender. These standards are rigid in construction, and, as has been shown, hard to overcome.

It may be the surprise of other people when they are faced with a man diagnosed with breast cancer which partly explains why Mr Lyons, who was diagnosed with the disease, believes that whilst the organisation Komen has done much to raise women’s awareness of breast cancer, they have not said very much about men. Mr Miller, a friend of Mr Lyons, went with his wife and daughters to a Komen lunch and his daughter recalls:

‘the greeters who were very friendly said to my mother, ‘are you the survivor?’ Then they went to each of my sisters and me. They didn’t even think to ask him’ (*The Oregonian* (USA) 09/12/03).

Here, the ‘greeter’ appears to have asked individuals if they are the ‘survivor’ in terms of the demographics of people most likely to have the illness, in this case an older woman, than a younger woman, as statistically breast cancer is more commonly diagnosed in post-menopausal women. By not asking men at all, this either shows a lack of knowledge of the disease in men, which is poor from someone working or volunteering within a cancer

care organisation, or it reflects a sense of disbelief that they are likely to meet a man who has had breast cancer. Men attending a fundraising or awareness-raising event for breast cancer are seen as being there in a supportive capacity, and women attending such events are automatically assumed to be the ones with a breast cancer diagnosis themselves.

A lack of information regarding men and breast cancer has meant that:

‘Every year, men all over the UK develop a disease that has such a stigma attached that most sufferers would rather die in pain than seek help for it. Other men simply refuse to believe they’ve got the disease at all, even after a doctor’s diagnosis. The disease is breast cancer, and the irony is that it has received extensive media coverage over the past 10 years. But this awareness campaign has, of course, been directed at women – 38,000 of whom in the UK suffer from the disease every year. What’s not widely known is that breast cancer also affects more than 250 men annually’ (*The Sunday Times*, 09/30/01).

Within this extended quote, what is apparent is how it is regarded as common knowledge that women are at risk of breast cancer – there has been ‘extensive’ reporting. This reporting has potentially led to the development of a ‘stigma’. A stigma can be viewed as a negative mark, associated with a particular quality or circumstance. In this sense, men fear the stigma of having a breast cancer diagnosis, and so may not want to seek medical help, either before, or even after, a formal diagnosis. There is an implication here that awareness campaigns and associated media coverage have helped to bring breast cancer to the forefront of women’s health, and such a goal may be necessary for men, if this stigma is to be overturned. In order for more men to be pro-active in seeking help, and to be able to come to terms with the diagnosis, this idea of stigma, and its negative connotations, needs addressing.

This ignorance is succinctly expressed within an article which advises readers:

‘Don’t be fooled into think it’s only females who can get breast cancer. It’s rare, but some men can be affected. Male breast cancer makes up around one per cent of all cases. Unfortunately, many men don’t realise that it’s possible for them to get it so they may ignore a lump until it becomes large. Early detection and fast treatment are key to improving outcome and survival, so awareness is vital’ (*Sunday Mail* (Australia) 09/18/05).

The use of the term ‘fooled’ expresses an idea that the lack of information about breast cancer in men has lulled the public into assuming that it is a disease of women, whilst also implying that people should be aware. This idea of awareness is raised again, but with a different purpose:

‘if men have breasts, they can get breast cancer. So why aren’t we always banging on about it? Shouldn’t we be promoting awareness, like the women do? No. Because male breast cancer is very rare. Only around 250 cases are diagnosed in the UK each year. There’s no point in raising awareness about something so unusual – blokes won’t end up more aware, they’ll just end up more anxious’ (*The Sun*, 09/29/05).

It is a valid argument that breast cancer in men is rare, and therefore health campaigns should focus on diseases which are more likely to affect men, such as cancers of the lung, testicles, and prostate. The idea that an awareness campaign would make men ‘more anxious’ rather than ‘more aware’ is an interesting one. There is an implication here that awareness campaigns may raise the profile of a health condition, rather than actually provide information about it; in this case, a breast cancer in men awareness campaign may make men more aware of the disease, but not actually instil in them any knowledge about it, for example a man’s incredibly low risk of developing it (when compared with a woman) and the available treatments and prognosis. The article appears to suggest that men would be worrying over something which ultimately is unlikely to affect them, and that this worrying would be more efficient when targeted towards something which is of higher likelihood. It is also assumed that men are anxious about their health, whereas this is not necessarily true for all men.

How awareness might be developed by both the health care sector and charities in the future

It has been shown that raising awareness is not a straightforward process: it is a problematic process for which there is not a simple solution. One desirable possibility is to place men in a more prominent position, in the hope of increasing awareness about their risk of illness, but in a manner which does not detract too much from the dominant group of women. It is the privileged position of the marginal man, in terms of him being able to see into the dominant group which provides an insight into how the standards of a social world produce exclusions, and how these might possibly be addressed.

Mr Kingsley, who was diagnosed with breast cancer, said he was frustrated during efforts to raise awareness as he felt that major health organisations ignored breast cancer in men in order to concentrate on raising awareness of breast cancer in women (*Sarasota Herald-Tribune* (USA) 10/02/07). A similar sentiment was shared by Mr Sala:

‘Breast cancer awareness month is a great initiative, but all of these places just advertising about women getting breast cancer makes me angry [...] If they simply put the word ‘men’ in there, they might take notice and begin to realise they are at risk of the same thing. If that could save even one life that would be a dream.’ (*Caloundra Weekly* (Australia) 10/20/10).

In these articles, men are expressing their wish to help other people, and yet they feel that organisations and schemes already in place are hindering rather than helping them do so. Whilst acknowledging that campaigns for breast cancer in women are of importance, they must not be organised in a way which has the potential to be detrimental to the health of men. The standards of the breast cancer community produce exclusions, as they are not able to incorporate men into their work. Men, in terms of their marginalised position, are able to see this, and the charities need to establish how they are to be included if they are going to be able to make breast cancer awareness month as fully inclusive as it should be.

As has been shown through above stories of men and women striving to raise awareness of breast cancer in men, charities have a key role to play in such campaigns, a role reflected in a number of articles. The Scottish Breast Cancer Campaign wants to highlight men in its awareness of breast cancer, and the only male director of the charity is going to do a sponsored run to raise money for research into this (*The Scotsman*, 06/16/00). *The Irish Times* acknowledges that:

‘Usually considered to be a woman’s disease, breast cancer can also affect men. A campaign hopes to improve early detection rates [...] breast cancer is largely viewed as a women’s disease because it is rare in men’ (07/24/07).

Within these two quotes, charities are portrayed as being important in highlighting not only the dangers of breast cancer generally, but specifically for men. There is within this the idea that awareness needs raising, and someone ought to do it: as such, charities are best placed for this, through the events they can oversee. A focus on building awareness is necessary in order for current and subsequent generations to be encouraged to be vigilant about breast cancer in men (*Metro*, UK, 10/14/10). This is a long-term plan, enabling men now to be better informed about their risk of breast cancer, so this knowledge can be passed on as appropriate.

A website is being launched in Australia,

‘in an attempt to help men access information – and there’s not a shade of pink to be seen. It’s also part of a push to increase community awareness about male breast cancer to at least alleviate some of the pressure these men face’ (*The Australian* (Australia) 07/22/06).

This stated avoidance of pink positions breast cancer in men almost as a disease separate from its female counterpart, but women are still included in the ideas about community cohesion, so that men feel less isolated after a breast cancer diagnosis. This emphasises the role women have in terms of healthcare and how they need to be aware of a health condition so that they can help others. It also reflects the isolation individuals may experience

after diagnosis, both physical and geographical. In a second story about online information:

‘Breast cancer is not just a woman’s disease. Inspired by one man’s story of survival, Men’s Health Network, the leading online men’s health authority, has launched an educational campaign daring men to be aware of their risk for breast cancer. Launched in recognition of Breast Cancer Awareness Month, Dare to be Aware: Men and Breast Cancer helps break through the often fatal barriers that can prevent men from getting an early diagnosis and treatment’ (*PR Newswire* (USA) 10/11/06).

The use of the word ‘dare’ here suggests men need to be brave (a dominant trait associated with norms of masculinity) and step into an unfamiliar arena, primarily one of health awareness, but focusing on a disease commonly associated with women. If men are concerned about threats to their masculinity by seeking knowledge about this disease, the brave and daring framework of the campaign protects against these threats by structuring it in such a way that if men use this education campaign to become more aware about breast cancer, then they are less at risk of damaging how others see them as masculine.

When Michael, who was diagnosed with breast cancer, was asked about what he thought might be different in the future, if he saw any changes, he replied:

‘no...not until somebody is willing to go, we’ll change it, and as I say, charities can do a lot more, whichever charities, I think government can do a lot, just say it can happen, it can happen, can’t it?’ (Michael, 07/05/11, p.30)

He believes it comes down to:

‘just education education education int it, once, once people realise it can happen, I think things will move forward’ (Michael, 07/05/11, p.31)

He concludes:

‘let’s just do it for men, just do a one week, or one thing, awareness that men can get breast cancer too. And just see how many eyes it open. Don’t mind. Never happen, will it? Never happen. But never mind.’ (Michael, 07/05/11, p.31)

Contained within these quotes is the opinion that charities and governments can do more than they currently are in terms of raising awareness about breast cancer in men, and the crux of this is education: once people are aware of their risk, they will be in a more informed position to take responsibility for their health. He is, however, pessimistic that this will come to fruition. He is almost resigned to this fact, resigned to being in marginalised position, and for future men with breast cancer to be in a similar position also.

A key question within this chapter is whether the balancing act of incorporating men whilst focusing on women as the majority user group is an area which could be resolved, or whether it is something which is always going to be there. Barbara, who works at a national breast cancer charity, says that:

‘I think it’s always going to be there, I think, I think it depends a bit about how brave we want to be erm putting our necks out a bit and then creating a reaction, and being able, being able to be sort of confident enough to be able to deal with the debate that might then follow, and we do get some of that debate on our forums, I think we’re quite good at managing that in a way that you know, where, the issues are aired without people being too sort of horrid to each other which is always a balancing act.’ (Barbara, 13/05/11, p.5)

Awareness of breast cancer is constructed by charities and organisations through their aims and objectives, and how they present the disease. From the quote above, maintaining a focus on the majority group of women as seen as the safer option, rather than ‘creating a reaction’ in terms of moving some of the attention towards the disease in men. There is a balancing act in terms of ensuring their limited resources are used efficiently and effectively,

but the minority group is still viewed as a potentially troublesome area in terms of maintaining good relationships.

When Barbara is asked about what she thinks may happen in the future regarding the involvement of men and other minority groups within charities generally, she replies:

‘I hope this will happen is that there’ll be more general awareness raising aimed at men about their risk of cancer and I hope breast cancer would be included in that as a sort of in a way a smaller issue because it’s not a cancer that that most men you know need to be too concerned about but it’ll also shouldn’t, shouldn’t be ignored, um, I mean there have been big initiatives around cancer awareness in other countries aimed at men but nothing very very big done here, um, so I hope that that will happen more [...] I mean we will continue to look at ways in which we can make sure we’re responsive to men without er pretending it’s sort of equality er equal impact in terms of a cancer.’ (Barbara, 13/05/11, p.9)

This does show Barbara is optimistic about what could be accomplished in the future in terms of including men within breast cancer awareness campaigns but again, there are not specific details as to how this could be accomplished. Many people have expressed this as a desire, but there is little dialogue as to how this could be achieved. Barbara refers to minority groups in general:

‘it can be a bit of a political minefield, getting that right, and there will be individuals who will feel we’re not doing enough for any one sort of particular minority groups and we have to sort of judge that I guess whether we’ve got that right or not, erm, and that you know will undoubtedly be remain as an issue.’ (Barbara, 13/05/11, p.10)

There is always a balance to be maintained, and arguably one charity cannot satisfy the demands of all its users, which is one reason why there are so many breast cancer charities as they all have different specific aims and objectives, even if they share an overarching aim such as finding a cure. Utilising the viewpoint of the marginal man, a minority group of breast

cancer patients may be able to offer assistance in terms of how it can be more inclusive to the people currently in need of its services, and the people who will be diagnosed in the future.

How gendered assumptions reproduce the normative assumptions of femininity and masculinity, and how these are linked to breast cancer

The normative assumptions of femininity and masculinity in Western culture see breasts as belonging to women and having a key role to play in their sexuality and their embodiment as women. Men are not seen as having breasts, and whilst the majority of newspaper articles in this dataset maintained a serious tone throughout, given the subject, some were light-hearted in their approach, given their target readership. As one article explains:

‘Believe it or not, men have breasts too. Nothing to compete with Liz Hurley, sure, but believe me it’s true – right under each nipple, there’s a tiny bit of breast tissue’ (*The Sun*, 04/11/03).

Another similar article in the same paper is about ‘moobs’ (a slang term which is an abbreviation of ‘man boobs’) and reminds the reader about breast cancer and advises to seek medical help if concerned (*The Sun*, 11/02/06). Moobs are also mentioned in an article which expresses health experts’ concerns that a rise in the number of men who are obese will cause rises in rates of breast cancer in men; this is because high levels of oestrogen have been linked to breast cancer in men (*Irish Independent*, 08/27/07). One other article explores moobs, and how they can be eradicated. Breast cancer in men is mentioned at the end, along with ‘clues’ as to how to spot it (*The Sun*, 02/04/10). There is an idea here that by making it appear light-hearted, it is moved away from being a discussion about a serious illness towards something more approachable. The focus is no longer on how a ‘woman’s’ disease can affect men, but how something innately masculine and almost jovial, ‘moobs’, can actually be hazardous to health. It is debatable whether such an approach would be utilised in articles focusing on raising awareness of breast cancer in women.

One idea of masculinity, that men should not need to ask for help, is acknowledged by Mr Woodcock who posits that the best advice he could give to a man who thinks he notices a symptom of breast cancer:

“is that if you have any doubt, get it checked out. Don’t leave it to chance, and don’t be too proud. The quicker you get seen to, the greater your chance of survival. Every man should be aware.” (*The Northern Echo*, 06/27/06).

Here men are acknowledged as being ‘too proud’ to ask for medical help, but they need to be able to counter this, in order to receive the help they may unfortunately need which may help them to survive their diagnosis. The strength associated with masculinity here comes from the ability to be able to overcome pride, not from being stubborn and ignoring possibly deadly symptoms.

Several articles focused on women who have taken it upon themselves to raise awareness of breast cancer in men. For example:

‘Up to 500 young men had a day to remember when student Katie Boltain dressed up as a Greek goddess and gave them a charity chest massage. The Salford University media, music and performance student rubbed oil on hairy torsos to raise awareness of male breast cancer’ (*Manchester Evening News*, 05/16/05).

Most women in these articles were wives, though, or women who had close relatives (not necessarily male) diagnosed with breast cancer.

‘TV star Gloria Hunniford is planning to champion the battle again MALE breast cancer [...] “People do tend to forget sometimes that breast cancer is also a male problem”.’ (*The Sunday Mirror*, 05/15/05, original emphasis).

This encapsulates an idea that as so few men are diagnosed, and assuming not all will want to engage in such activities, the assistance of women is needed in order to spread the awareness message. This may be especially

true for women who have closely experienced a breast cancer journey, and therefore speak from a knowledgeable position.

Mrs Dougan, who lost her husband to breast cancer is going to a charity event and will:

“pass out T-shirts [sic] informing people that men aren’t immune to the disease. If me being active can save just one man so he can enjoy his grandchildren later in life, then I’ve done my job” (*The Evansville Courier* (USA) 09/14/09).

The use of ‘job’ relates to the idea of obligation, that people within a minority group should use their position to help others. Whilst this has been seen so far in quotes from men, this is now being seen in women; there is a sense of aiming to raise awareness to help men, but also to protect their family and friends from experiencing what these women have endured.

‘With June being national Men’s Cancer Awareness Month, Mrs Cooper is trying to spread awareness of [male breast cancer] and what can be done to tackle it. “We did not know that men could get breast cancer before Stephen was diagnosed,” she said. “There is a lot of publicity about women and breast cancer, but men need to be aware that they can get it too.”’ (*Malvern Gazette*, 06/16/08).

This quote emphasises the relationship between the Coopers and how both the man and woman perhaps share this obligation to do what they can to instil knowledge in others. In an article about a woman sharing her experiences of her husband’s breast cancer diagnosis, it says the Junior Service League has ‘launched a campaign of billboards and bench signs with the heading “Real Men Get Breast Cancer.”’ (*The Grand Junction Daily Sentinel* (USA) 10/25/09). This is a clear reference to masculinity, and how a breast cancer diagnosis does not make a man less of a ‘man’.

Concentrating on this idea of awareness, on a British forum a member of staff asks:

‘Do you feel there is a need for more breast awareness to be addressed at men specifically? How can men be best approached about breast awareness? Do you know of any men who are breast aware? If so, what might have prompted them to be breast aware?’
(*apNHI*, British1, 15/01/09)

Whilst this post is in the men’s section, the post contains specific questions, which are ambiguous as to whether it is aimed at men and their acquaintances, or perhaps female users of the forum. This is of importance as it contains an assumption as to who the charity believes is using this area of the forum; the assumption that women are going to be reading a post in the section of the forum designated to breast cancer in men. Regarding the replies, one man thinks there needs to be more information available so if awareness is increased men have appropriate information available to them. Another man argues breast cancer awareness should be aimed at everybody. The first man replies and says there is little economic viability to screening men and perhaps

‘any raising of awareness in men would be detrimental to the many other cancers with more subtle symptoms and a much lower survival rate’ (*gearchange*, British1, 21/01/09).

One man writes on another forum that:

‘I know that we [men diagnosed with breast cancer] are few and far between (only 300 diagnosed a year). I am hoping to raise awareness of BC in men. Of course it is not all about the men. Women have a much tougher time with their Mastectomies [sic] and it is nice to support each other’ (*JamesR*, British3 16/04/12)

To which a man replies,

‘I am only too happy (or too eager?) to share experiences with other men who are becoming more in touch with their feminine side than they ever thought possible’ (*Bounce*, British3, 16/04/12)

In its basic form, mastectomies are similar for men and women, although of course there will be differences, and it is probable that experiences will be as unique for any two women as they would be for a man and a woman. Taking this into consideration, there is an implication within this man's comment that women will find mastectomies 'tougher' due to other factors, such as the roles breasts play in a woman's life, and the emotive connotations these have, which men do not. Consequently, by virtue of being a man, a mastectomy will have less of an impact on male patients. This links with the comments made by the second man in this thread, in that by having breast cancer, men are having to engage more with their 'feminine sides'. Breasts are commonly viewed as feminine, with regard to their connotations of motherhood and female sexuality, areas with which men are less likely to be familiar. Assumed within this comment is that men are required to engage with these areas in order to establish their identity as a person diagnosed with breast cancer, and participate actively within such forums. It is likely that a number of women diagnosed with breast cancer will feel just as uncomfortable as men with getting in touch with traditional ideas surrounding femininity, yet there is no indicator that there could be an alternative route of engagement, one which places less emphasis on these traditional ideas of femininity, and places more emphasis on perhaps information and support which is more gender neutral.

Continuing with this thread, a woman comments that:

it's good to be reminded that we women don't hold the monopoly on breast cancer and need to be a bit more sensitive to the fact that men get it too. There are plenty of 'girls only' and 'boys only' cancers but we've all got breasts (*Alexandra*, British3, 16/04/12)

The original poster responds:

'there is indeed a major difference between men and women with BC. For a start, it is a hell of a lot more trauma for a woman to have a mastectomy, just the psychological effects alone. On a different scale, as there are so few men that get BC, [there] is a lack of support for us. I see that as no one's fault. You cannot have support groups if there is no one else to turn up (*JamesR*, British3, 16/04/12)

Within this post are two points, the first being that as there are relatively so few men diagnosed with breast cancer, it is consequently understandable that there is a paucity of support available, and the second being that men may be available but do not wish to become involved. However, there is the possibility that there are other men who are not accessing forums or utilising what support there is, and would wish to become involved if the facilities were available and they knew how. There is a desire within posts to encourage more men to become aware of breast cancer. One man, who is undergoing investigative tests, writes:

I posted to encourage other men to get checked if they find anything. I was mildly worried that I would get there and the doc would tell me I imagined it all [a lump in his nipple]. I was never worried about having a “woman’s disease”. It doesn’t strike me as womanly if it can kill you (*FoodFather*, USA, 15/04/11)

Whilst breast cancer is seen as a feminine disease, this poster is commenting that he views it as less ‘womanly’ because it has the potential to kill. Here, normative feminine attributes such as being caring and nurturing are contrasted with those of a disease which can maim and kill. By acknowledging this potential outcome, breast cancer has moved from the pink niceties of traditional femininity towards something darker. This transition is a break away from femininity and as such this poster is highlighting that men need not worry about having a ‘woman’s disease’ as breast cancer is much darker than perhaps the connotations imply.

Men with a breast cancer diagnosis are a minority group within a much larger majority, and are having to become more familiar with both their health and the breast cancer world, as they enter this female-dominated environment. Raising awareness and self-examination are seen as key to the early detection and treatment of breast cancer, and if men were to be directly mentioned in such posts and campaigns, they too would develop the awareness needed for early detection. The assumption that breast cancer is so rare in men, therefore regular checking of breasts is pointless, may be a fair one, but then again regular checking is there to know what is normal for

that individual, and it is these changes away from normal for the individual which are what women are encouraged to report to doctors.

A thread is started on the US site about a news report regarding the breast cancer diagnosis of the male drummer from the band KISS. The first response says:

‘Fortunately for us women there is lots in the news regarding breast cancer, but most people never hear about bc in men unless it hits a celebrity. I wonder how many men die not knowing that their original cancer was in their breast? True, it is more rare in men, but the fact that men do get this type of cancer needs to be more in the news (*Honeydew*, USA, 23/11/09)

Many female celebrities are in campaigns dedicated to raising awareness of, and funds for, breast cancer, both celebrities who have been diagnosed with breast cancer, and ones who have not. The idea presented in this post is that breast cancer in men will only get more media attention when it is a famous man who has been diagnosed. In non-celebrity men, breast cancer may be seen as unusual, and therefore newsworthy in this respect, but in a man who is well-known, it is viewed as being more newsworthy as the public already has an interest in those in the public eye. Media readers/viewers may skip over an item about an unknown man with breast cancer, but this prior knowledge of a well-known person may make them pay more attention. It is this attention that can be capitalised upon with regard to breast cancer campaigns. This poster is highlighting this, by explaining how people only hear about breast cancer in men when a famous man makes his diagnosis public, and these men are few and far between.

Another poster agrees with what has been said, whereas another says that when she advised her husband to do breast self-examinations he laughed. Herein lies a point which anecdotally indicates that even if men are aware of breast cancer in men they still may not take it seriously. For a man to examine his ‘breasts’ he needs to have enough knowledge that he can follow a guide for women and breast self-examination, a guide which may not be that useful to men, given the shape and size differences between men and women’s breasts. Self-examination needs to be perceived less as a

‘feminine’ activity, and more as one which could be life-saving generally, to allow for more people to feel comfortable doing it so that it can work as an early-detector of cancer.

This relationship between men and their breast tissue is not one which is explored, and many people may be embarrassed to have to consider it. Mr McGeevor, explaining how he found his breast lump, says:

“Men are supposed to be macho about things like that, so I just shrugged it off until I started breaking out in hot sweats [...] Men have got to forget this macho rubbish and check themselves out regularly. When you have a shower it doesn’t hurt to check your body out” (*Sunday Mercury*, 08/07/05).

Similarly, Mr Scrivens:

“went through hell...I’ve always been a real man’s man – I did a hard, manual job and provided for my family. To be told I had breast cancer was a real blow. But now I believe it’s my job to make people aware’ and whilst he did not feel embarrassed about it, he can understand why some men might be (*Mirror*, 08/31/05).

Mr Mayes volunteers to hand out leaflets about breast cancer in men but has found when doing so that ‘Embarrassed men avoided his gaze, hurried past or crossed to the other side of the road to avoid him. Breast cancer is often thought of as a ‘women’s issue’ – but David bears an 11 inch scar across his chest as a lasting reminder of his own battle with the disease’ (*Scottish Daily Record*, 09/30/05). The concept of sexism is more commonly applied to situations in which women are discriminated against, so it is a powerful statement for a man to say that he felt discriminated against solely on the basis of his sex.

Gendered assumptions, and gendered support

For women who have been diagnosed, there are a variety of support groups available, but it is not clear as to how these groups include men, as shown by a forum user who asks:

‘Gents, have you been to a Breast Cancer Support Group? There are a few in my area and I was considering attending to talk with local co-sufferers, but never actually talked to any of them with a view to attending meetings. It transpires that my wife enquired on my behalf and was more or less told that I wouldn’t be welcome. It was felt that women can suffer differing side effects and that they may be unwilling to discuss [them] if a male was present. One suggested that I should attend a generic Cancer Support Group instead! I could get quite annoyed about this if I let myself, it is nothing more than sexism in my opinion’ (*MattM*, British1, 31/01/06)

Through this man acknowledging that breast cancer is rare in men, there is an implied meaning that this can act as justification for why men are excluded from breast cancer support groups. It is justification in the sense that women are the majority patient group, and as such groups tend to be organised by women and likely to focus on issues of concern to women, there is logic in keeping the group female-only in order to create an environment in which women feel comfortable. Therefore, there is an argument to keep such groups female-only. However, unlike other contexts which are entirely female, breast cancer does affect men and as such there is not total justification for excluding men entirely from such groups. There is a balance here between giving people diagnosed with breast cancer the support they need, in a safe environment, but ideally without causing offence to others.

The final reply comes from a woman who says she has two men in her support group and they are just as entitled as her to be there. The suggestion presented, that men have ‘given up because nobody seems to listen’ is very important, and could be applied to a number of groups of people and organisations. If ‘nobody seems to listen’ refers to charities, officials, people with the potential power to alter and change situations, then it needs to be considered why these people would be accessing such a forum. As is shown in the above posts, the forums are seen as places for the exchange

of support and advice from other people who have been in that individual's situation and as such, people belonging to charities, or organisations, may well not be listening because it is not 'their' environment, as they have not necessarily been affected by breast cancer. Whilst the forums are usually moderated, in terms of ensuring no individuals breach the forum guidelines, they may not have the attention paid to them that this individual feels they are worth. It is interesting that this man is still posting on the forums, even though he acknowledges that other men have given up. Contained within this is an element of hope, in that whilst other men may feel that no one is listening, this man does feel that there is the potential for his participation within this forum to make a difference.

The age of men diagnosed with breast cancer arose as a potential reason for the apparent lack of male engagement with charities. Using the call for respondents for this research project as an example, Richard was surprised at the small number of responses obtained. When asked to elaborate, he supposed:

'it's difficult to track down the older gentlemen cos they're probably not social networking savvy or computer savvy and not really up to talking about it, too old-fashioned perhaps' (Richard, 20/06/11p.4)

As men tend to be diagnosed with breast cancer at a later age this is a valid remark in that this generation of men are less likely to be computer literate, and this will have to be taken into consideration with regard to services offered, both now and in the future as computer literacy does become more widespread.

Richard suggests that men may not feel:

'that they can open up and talk about, talk about their problems or what to talk about their problems openly with anybody else, I think women may be a bit a bit more used to doing that and more comfortable doing that other than men are probably.' (Richard, 20/06/11, p.11)

There are a lot of assumptions here, and if one man is assuming these things, are other people, to the detriment of charities and ultimately to the detriment of men diagnosed with breast cancer? Equally, it is a generalisation to assume all women do this, as women (like men) are not a homogenous group.

How does this shape men's experiences of breast cancer?

It is clear that knowledge of breast cancer in men is not held by everybody, including those who have been affected in some way by breast cancer, as described by Mr Tull talking about his breast cancer:

‘Sitting in the waiting room of the breast cancer clinic, I immediately noticed I was the only man. Around me, 30 or so women looked up from their magazines in bemused confusion. Then, the lady next to me leant over and tapped me on the shoulder. “I think you’re in the wrong place, dear,” she said. “We’re breast cancer patients.” She was totally shocked when I said: “So am I.”’ (*Daily Mail*, 06/24/08).

This use of the word ‘dear’ may appear patronising, or as though talking to a child, as though it is obvious that only women would ever need to be in a breast cancer clinic, and so it is perhaps stupidity on the part of the man that he has ended up in the ‘wrong’ place. This ‘knowledge’ that men do not have breasts is expressed by Mr Fasano, who explains:

‘First of all, they said, breast cancer’ and I said ‘what? Men don’t have breasts [...] I have a chest.’ (*York Daily Record* (USA) 11/05/06).

This exclamation reflects the surprise that his assumption that men do not have breasts was wrong, an assumption held by many people.

A key way in which this issue of stigma can be addressed is through men being open about their breast cancer diagnosis. When Stuart Gilder was diagnosed with breast cancer, ‘he decided to be open about the diagnosis with friends and family, and their most common reaction, he says, was “you

have got to be joking”.’ He says he was surprised by the ignorance people have about breast cancer in men (*The Sunday Times*, 09/30/01).

Mr Hadfield believes there is a lot of ignorance around breast cancer in men and his ‘main aim is to make men aware that breast cancer is not just a woman’s disease’ (*Daily Mail*, 10/15/02). Similarly, Mr Kay:

‘has taken it on as personal mission to talk about male breast cancer every chance he gets – to friends, family, people at his aquafit class and men at the health fairs he attends. He also volunteers as a telephone peer support counsellor through the Canadian Cancer Society’ (*The Hamilton Spectator*, (Canada), 04/12/03).

As these men show, they have actively taken it upon themselves to ensure other men are more informed than they were. In doing so, they are engaging with activities not usually associated with masculine endeavours, for example the telephone counsellor, and speaking publicly about illness. These activities, whilst perhaps at first detracting from a masculine sense of identity, especially to the spectator given the breast cancer context and female connotations, may actually be enhancing masculine qualities such as strength, and helping to establish an alternative approach towards reflecting masculine concepts. These quotes showcase the need for, and desire of, men with breast cancer to speak out about their illness so that their experiences may be of use to others. Because breast cancer in men is a rare diagnosis, it can be posited that there is an obligation to help others: as so few people are diagnosed, and as such there is so little research information, those who are diagnosed need to be frank about it in order for data to be collected so that gradually more knowledge is gained about the illness.

Herein, there lies a balancing act, almost, with regards maintaining a masculine façade – going public with a breast cancer diagnosis may potentially threaten a masculine identity, as ill-health can be viewed as a sign of weakness, a lack of strength (especially given the serious nature of cancer, its long-term treatment options, and prognosis), but this perhaps is countered by using the illness experience to help others, and thus be of strength and knowledge, which may in their turn strengthen the masculine identity held by an individual. One individual who clearly reflects this is:

‘A firefighter who discovered a lump on his breast is now trying to raise awareness of the dangerous condition among the region’s men. Eddie Cooper, 36, from Hebburn, was stunned to discover a lump on his left breast only months ago [...] Now Mr Cooper is teaming up with colleagues at Barmston Mere Training Centre in Washington to raise the profile of male breast cancer’ (*The Newcastle Evening Chronicle*, 09/06/05).

Being a fire fighter is still seen as a masculine career choice, so here there is a very masculine man, with his colleagues (statistically, his male colleagues), striving to raise awareness of this illness. Men who hold such positions within society are arguably well-placed to remind the public there are many aspects to each individual and as such a diagnosis of a particularly ‘feminine’ illness does not automatically detract from inherent ideals of masculinity.

In reference to men receiving a rare diagnosis, and associated obligations, Mr Scott, who has had breast cancer, took it upon himself to raise awareness of breast cancer, when he saw both the pink ribbons for breast cancer awareness month and the lack of men included (*St. Petersburg Times* (USA) 10/20/05). When this is considered alongside Mr Goldstein:

‘a male breast cancer survivor from New Jersey, [who] wants men to know they can get the disease too. In fact, he says, in the rare cases when men do get breast cancer, it’s more likely to kill them – partly because they aren’t as aware’ (*Seattle Post-Intelligencer* (USA) 06/07/04),

This awareness campaign is not just about raising awareness in that a man could be diagnosed, it is specifically about saving lives as well. Herein lies the argument that if no-one is going to help men, they need to do it themselves, a similar attitude perhaps to the one held by the women who began their breast cancer awareness journey and movement for women. Whilst breast cancer is seen as a feminine illness, by a man standing up for himself and helping others, this is a very masculine trait, being strong for himself and for others, and aiming to be influential. Here again is seen a

balancing act, how a breast cancer diagnosis may have the potential to damage one's masculine self, and yet such acts may in fact counteract this, and help to strengthen it.

This willingness to go public with a breast cancer diagnosis is praised by a doctor, who notes 'that while men are becoming educated about prostate cancer, not many are aware of breast cancer because of the low rate among males' (*The Cincinnati Post* (USA) 10/27/06). This appears to indicate the health awareness campaigns aimed specifically at men are successful in meeting their objectives, and therefore building on this success for breast cancer in men is possible if men are willing to be figureheads. Admittedly, not all men are willing to engage in such activities and therefore men like Mr Fant, who has been diagnosed with breast cancer, are vital as he:

'sees his role now as one of raising awareness among men that breast cancer isn't gender-specific. "Most males still are not concerned. I believe those that have had the disease are a bit shy about alerting others. I'm not shy, so my mission is to tell the story," he said' (*Chattanooga Times* (USA) 09/29/07).

These men in these quotes, whilst acknowledging that not all men would wish to go public with a breast cancer diagnosis, have been able to use their situation and experiences to help others, a move which has been praised by medical professionals. There is also support for the argument that there is a sense of obligation, as some individuals do not wish to participate in campaigns, those who do are perhaps even more beholden to do so, as they may be the minority within an already-significant minority group.

It has been suggested that one way of stepping out for the breast cancer awareness campaign in general, and as such being more accessible for men, is to rename breast cancer 'chest cancer'. Mr Avery, who was diagnosed with breast cancer:

'is now campaigning for breast cancer to be called "chest cancer", with the hope of raising awareness of the disease among men' (*Yorkshire Post*, 06/17/09).

This man used his experiences to publicise the fact that men can get breast cancer too, and modelled in the Breast Cancer Care fashion show (*Echo*, UK, 03/13/09). He believes there is a stigma attached to men receiving a breast cancer diagnosis, and as such this is a taboo area for men. By renaming the disease and calling it ‘chest cancer’, thus naming it after a part of the body which is more generic, and possibly seen as more masculine than feminine, this can separate male patients from the female connotations, but is anatomically inaccurate.

Breast cancer in men was often mentioned in reference to charity events which were being organised, either by charities in support of men, or by men in support of charities. The Komen Race for the Cure is a key event in the breast cancer awareness and fundraising calendar in the United States, and as such was featured in a number of articles. One prominent male featured was Mr Goldstein who became an advocate for survivors of breast cancer and tried to run the 1992 Race for the Cure in New York. However, the race was then for women only. He and his family entered using only their initials and surname and were challenged at the start. The race is now open to everyone (*Evansville Courier and Press* (USA) 09/14/00), arguably thanks to the efforts of this family to make the event inclusive for all people diagnosed with breast cancer. Mr and Mrs Miller, who have both been diagnosed with breast cancer,

‘will be among the 2,000 breast cancer survivors and 20,000 running or walk in today’s Susan G. Komen Race for the Cure in Central Park (*New York Daily News* (USA) 09/15/02).

‘Now more than 90 percent [sic] of the 112 events around the country have races that welcome men [said a spokeswoman for Komen] although some of the events don’t allow men to run competitively’ (*The Oregonian* (USA) 09/12/03).

This original exclusion of men is important as it clearly reflects how one part of the breast cancer awareness campaign saw itself as being solely for women, by women, regardless of the men who may be affected by breast cancer (whether this be through their own diagnosis, or through having female friends or relatives diagnosed). By entering using only initial and

surname, this acknowledges the possibility that men would not be allowed to participate, a possibility which became apparent when he was ‘challenged at the start’. In this example a man is clearly being ostracised from the event, he has shared experiences with the women allowed to participate, and his female relatives (who have not had breast cancer) do not share these experiences and yet they are the only ones allowed to participate according to event rules. It is explained that whilst the majority of races now do welcome men, in some instances they are not allowed to run competitively, so men are still not fully included (although it could be argued that in most competitive races – not just charity events – men and women do compete separately).

Conclusion

This chapter has explored how awareness of breast cancer, and more specifically, the lack of awareness of breast cancer in men, are linked to hegemonic femininity and reinforce hegemonic masculinity. Hegemonic masculinity in Western culture can be seen as having qualities such as physical strength, emotional restraint, an ability to provide for and support others, and a daring, risk-taking attitude towards danger.

Awareness of breast cancer, and awareness of the support available to people, has been shown to affect individual’s involvement within the wider breast cancer community. Even if a man is aware of his potential risk of being diagnosed with breast cancer, this awareness needs to be shared by other people in order for him to be more readily included with this specific community. Institutions construct awareness through their campaigns, and how these are focused on specific demographic sections of the population, for example raising awareness of breast cancer in younger women and encouraging this age group to conduct self-examinations and check their breasts in order to be in a position from which they can tell in the future if anything has changed. In line with this, charities see awareness as gendered, with the dominance of the pink ribbon, and an over-arching focus on women. Whilst this is understandable as they are the people most likely to be diagnosed with breast cancer, this narrow focus could be damaging to

other people who may not be aware of their risk, nor have any way of discovering this.

As such, normative assumptions surrounding masculinity and femininity are reproduced, and are firmly linked with breast cancer. Monthly self-examinations position women as taking care of their health, showing awareness of their bodies, and being ready to seek professional help if anything is suspected of being wrong. The lack of awareness of breast cancer in men, and the lack of campaigns to get men checking themselves helps to strengthen the view of men as caring less about their health than women, and not being as pro-active in terms of seeking help if they are suspicious. In turn, this influences men's experiences of breast cancer, as they may often have entered the breast cancer community in terms of illness before they or anyone else has even realised that anything is wrong. It can be seen as a perpetuating cycle of charities and organisations campaigning to raise awareness of a 'woman's disease' whilst men remain unaware that they may even be at risk.

Chapter Eight

Conclusion

Overview of aims and objectives

The dominant culture of the feminised pink ribbon associated with breast cancer is an example of how gender and illness are entangled, and how it is difficult to separate one from the other. Given its unique positioning (arguably the pink ribbon and its association with breast cancer is the most identifiable ribbon linked with an illness internationally) breast cancer has been used as a case study for exploring this relationship between gender and illness, as it has created and developed for itself a central place in terms of the fundraising and awareness. Men who are diagnosed with breast cancer become involved with this culture in a way which they may never have thought possible. Consequently, men with breast cancer are a significant example of how issues associated with identity are likely to be impactful, as individuals may need to reconsider certain aspects of their lifestyles or future plans: the future men with breast cancer face may be considerably different from what they had imagined before their diagnosis, given cultural references, norms and values, which might currently be beyond their understanding, or ability to relate to. It is these assumptions within the breast cancer culture, and its norms and values, which are the foundations for the identity issues men can face straight after their breast cancer diagnosis. To understand men's experiences of breast cancer within this culture, it was necessary to explore what the cultural assumptions are, and their impact upon the breast cancer community as a wider whole.

To understand the experiences of men diagnosed with breast cancer it was necessary to not just focus on individual patients, but on their stories in terms of their own experiences, and how they have tried to integrate into the social position in which they have found themselves. As breast cancer is so closely related to the community that surrounds it, the experiences of men with breast cancer needed to be considered alongside an understanding of the social world of this breast cancer community. The focus on men as a minority group within the larger breast cancer community allowed their

experiences to be a window into the norms and values of this culture. Developing this further, the case study of men with breast cancer provides an understanding regarding how social worlds are built and maintained.

Key findings of thesis

Receiving a breast cancer diagnosis poses challenges to hegemonic masculinity. Bury's concept of biographical disruption, that individuals diagnosed with a chronic illness will be able to redevelop their biography, was found to be insufficient, in that the assumption that people will be able to do this is misplaced. Men diagnosed with breast cancer were unable to do this, given the lack of information and support generally available. This showed the value of utilising Park's idea of the marginal man, allowing men with breast cancer to be seen as members of the breast cancer community, but remaining on its periphery.

Men, from their diagnosis of breast cancer through to their treatment and beyond, challenged the sense of hegemonic masculinity. As the majority of men in this position were unaware of the possibility of being diagnosed with breast cancer, their lack of knowledge placed them in a vulnerable position compared with that associated with Western ideals of hegemonic masculinity. Men were no longer able to control their situation, as the information needed to gain this knowledge and regain this control was not available, resulting in these men being unable to make fully informed decisions regarding their treatment. Public campaigns and the media portray breast cancer as being only for women, and this has detrimental consequences for men. This lack of control and dearth of knowledge reflects Star's idea of being uncommon, and the effects of this. Social groups and their social worlds are often ill prepared for the specific needs presented by rare groups of people, and this is especially relevant when the needs of the dominant group of people have to continue to be addressed also. It has been shown that it is difficult to address the needs of the minority group of breast cancer patients, whilst still allowing for the requirements of the majority group, who are numerically the dominant users of the services. The focus on the breast cancer community as a group of women was apparent, and as such challenges hegemonic masculinity as men

are placed in a position from which they are sectioned and marginalised from the dominant group. The dominant group is hard to penetrate, due to the lack of knowledge about their illness, as well as the lack of awareness. Combined, these impact upon the changing identities of male patients.

Breast cancer is positioned as a disease of women, and men are encouraged to participate as supporters. Awareness campaigns embody ideals associated with hegemonic femininity such as following heterosexual ideals and being feminine, and men with breast cancer are entering this area of hegemonic femininity at the same time as they potentially are having to be removed from ideals of hegemonic masculinity. Consequently, men find themselves at the confluence of hegemonic masculinity and hegemonic femininity. As such, men are marginal members as they are on the outskirts of one community and yet not quite able to be assimilated into another.

It was apparent that men and women with breast cancer had different experiences in terms of participating within the wider breast cancer community. Ideas of femininity and masculinity were interpreted in different ways, which could all influence how involved individuals wished to become within the community, as well as how accepted this involvement was viewed by others. Often, a split between gender and illness was visible, with emphasis placed on one rather than the other. A focus on gender identity meant women were able to access the breast cancer community as there was clear emphasis on ideal of femininity and womanhood. This meant it was harder for men to access the community, as they lacked these accepted ideals. To position people as patients primarily, and (wo)men second would be more difficult, due to the paucity of information available for men, and the norms and values of the breast cancer community as a whole are too rigid to include successfully men with breast cancer as the deviant case. It is these standards which have produced these exclusions, and even if illness identity did become the focus, it is probable the breast cancer community would struggle to fully incorporate this. Identity is a continual process and involves a balance between an individual's illness identity and their gender identity. Whilst men and women with breast cancer have their diagnosis in common, if gender identity is viewed as dominant then this shared illness will be seen as secondary, firmly positioning men on the outskirts of the community. Femininity unites

women within the breast cancer community, showing gender identity does have an important role: in order to be satisfied with their participation, men may have to accept this.

The pink ribbon associated with the breast cancer community is embraced to varying degrees by men, ranging from a full embrace through to a questioning of its appropriateness for men, and an inadequacy in terms of reflecting to the public the reality of breast cancer for men. Women do not all agree with the pink ribbon, as it can be seen as trivialising what is a serious and potentially deadly disease. The gendered assumptions around the colour pink influenced the extent to which individuals felt they could be included in its campaigns, which reflects the balance between one's illness identity and gender identity. The pink ribbon has accrued many great accomplishments, but it is necessary to consider this alongside how it can be developed in the future to better reflect those people diagnosed with breast cancer.

Awareness of breast cancer, and specifically the lack of awareness of breast cancer in men is linked to hegemonic femininity and reinforces hegemonic masculinity. Awareness of the disease and awareness of available support was shown to affect people's involvement with the breast cancer community. For even if a man is aware of his risk of being diagnosed with breast cancer, this awareness needs to be shared by others in order for him to be accepted more readily into this community. Awareness is constructed through institutions' campaigns, and how they focus on specific sections of the population. As such, charities see awareness as gendered, through the dominance of the pink ribbon and the focus on women. Although this is understandable, such a narrow focus could be damaging to people who are not aware of their risk.

Consequently, normative assumptions regarding femininity and masculinity are reproduced, and closely linked with breast cancer. The lack of awareness of breast cancer in men reinforces the view of men as being less concerned about their health than women are, and also being less pro-active in terms of seeking help as soon as they are suspicious. In total, this can be seen as a cycle of organisations and charities campaigning to raise

awareness of, and funds for, a ‘woman’s disease’, whilst men remain on the periphery, often unaware they may even be at risk.

In terms of how gendered assumptions about breast cancer shaped men’s experiences, men were often viewed as being ‘wrong’, for example medical staff expecting them to be female, and so addressing them incorrectly. This shows how men constantly experience the general lack of awareness about breast cancer in men. Men often felt that they were unwelcome at breast cancer charity events which were advertised as being for women only, as the emphasis was placed on women participating in order to help other women, even though many of the women participating will not have had a breast cancer diagnosis, and these men have. For many men, their experiences of breast cancer involved a balancing act, in terms of going public with their diagnosis, which may threaten how other people see them as masculine, or countering this by using their strength and knowledge (two features of hegemonic masculinity) to raise awareness and help others, and so strengthen their masculine identity.

Contribution to knowledge

This thesis has used breast cancer as a case study for exploring the relationship between gender and illness. The unique positioning of the illness reflects the intricacies regarding gender and illness, as the culture surrounding breast cancer as a whole has placed the disease as a central part of the fundraising and awareness calendar. To understand men’s experiences of breast cancer within this, the cultural assumptions needed to be addressed.

Bury’s concept of biographical disruption has been used to explore the ways in which people develop and evolve their identities following the onset and diagnosis of a chronic illness. Contained within this is the assumption that such a reconstruction of identity is possible. However, men diagnosed with breast cancer lack information and are in a world which is fundamentally contradictory, without the availability of resources to address. As such, another theoretical framework is required.

Park's concept of the marginal man has been used to show the positioning of men with breast cancer within the wider breast cancer community, and how a man can be part of two cultures, in name, and yet not fully a member of either. Marginal men have a double consciousness: though they are marginal, their position is privileged as it enables them to have two viewpoints, and see what people of an included position are not able to see. The ideas of the marginal man and marginality were developed through other members of the Chicago School, with Stonequist's development showing how men with breast cancer can make a contribution to the breast cancer community and yet not be fully assimilated.

To understand the experiences of men diagnosed with breast cancer it was necessary to not just focus on individual patients, but on their stories in terms of their own experiences, and how they have tried to integrate into the social position in which they have found themselves. As breast cancer is so closely related to the community that surrounds it, the experiences of men with breast cancer needed to be considered alongside an understanding of the social world of this breast cancer community. The focus on men as a minority group within the larger breast cancer community allowed their experiences to be a window into the norms and values of this culture. Developing this further, the case study of men with breast cancer provides an understanding regarding how social worlds are built and maintained.

Strauss' concept of social worlds, reflecting the processes and relationships found in a given phenomenon explores who truly belongs in a given social world. They generally do not have an inclusive membership, but do demand certain characteristics from people wishing to be involved. All individuals are part of multiple social worlds, leading to multiple identification. The concept of social worlds was developed further by Star, arguing for what happens when they become too rigid, and it is the deviant case which allows this rigidity to be seen. Men with breast cancer are the deviant case reflecting the rigidity of the wider breast cancer community. It is the standards produced by the social world which produces the exclusion, and forces the individuals concerned to be between worlds. This broadens the work of Park and Stonequist as it shows how an understanding of marginality is not solely based on people, it involves objects also.

This thesis extends recent and current work focusing on a gendered element in health research. Wenger and Oliffe (2014) examined the experiences of men diagnosed with cancer and how they engaged with illness self-management as well as help-seeking behaviours. There were three broad strategies: fortifying resources, maintaining the familiar, and getting through. The men drew on a variety of performances to respond to contexts demanding the embodiment of Western masculine ideals.

As has previously been discussed, there is a relatively small amount of social science research on men with cancer other than prostate cancer, and in particular, little research on breast cancer in men. This perhaps misses an ‘opportunity to describe similarities and differences in and across men’ (Wenger and Oliffe, 2014: 109) as well as between women and men. If researchers are to understand gendered patterns in the experiences of men with cancer then there is a need to consider the wider intersections of cancer and masculinities. This thesis has, in part, addressed this: the experiences of men diagnosed with breast cancer have been explored, focusing specifically on ideas surrounding masculinities and hegemonic masculinity, and the involvement of men as a minority patient group within a much larger majority patient group. If men’s experiences of cancer generally are not well researched, then men’s experiences of breast cancer are even less researched: as such, this thesis is addressing this area of researching from a specific angle and can contribute to wider ranging discussions.

Wenger and Oliffe (2014) found there were three broad strategies for help-seeking and self-management in the men who participated in their research. The first, fortifying resources, meant ensuring people have enough resources to deal with the uncertainty cancer brings. This included developing their knowledge about their illness, being able to make appropriate decisions and consider what information is credible. My research contributes to this discussion as it highlights ways in which men with breast cancer arguably have a further struggle when compared with men diagnosed with another form of cancer: the paucity of information readily available about breast cancer in men means that men diagnosed with the illness are not well equipped to make informed decisions about their healthcare.

The second strategy was maintaining the familiar, trying to lessen the impact of potential disruptions, such as continuing to be active, work, and managing other people's perceptions about them, trying to be seen as people first and patients second. The third strategy was getting through, men restricting their emotions and trying to distance themselves from their feelings. In conclusion, the article showed men manage their cancer in different way, and there are commonalities across different types of cancer, in part due to the social construction of cancer. This study was developed from previous research, especially that considering challenging assumptions about men and help-seeking behaviour, or lack of. In turn, this thesis builds on this in terms of contributing to knowledge about the experiences of men with cancer, particularly breast cancer as an under-researched area. Help-seeking behaviour (or rather, the lack of) is closely intertwined with Western ideas surrounding hegemonic masculinity and so the findings of this thesis can contribute to debates surrounding hegemonic masculinity and its influence with regards to health and health behaviours.

Breast cancer as a disease does continue to be researched in depth. Pudrovska et al (2013) used data from a longitudinal study and the relationship between occupation at age 36 and later incidence of breast cancer. Men were not considered, although the longitudinal study does include men. Clearly, the objective of this study was to look at breast cancer and higher-status occupations in women, but this still highlights the need for there to be more research conducted into men diagnosed with the disease.

This thesis extends current work in terms of developing the gendered element to health as well as contributing to an under-researched area. Linking these two together is the work of Bottorff et al (2008) who researched the role of women at prostate cancer support groups. Through participant observation and interviews, they looked at why women attended these groups, and what benefits they gained from attendance. Their results showed that women who participated in these groups went through periods of self-reflection, tension and uncertainty regarding their attendance. They gained a greater understanding of the disease, felt they could better support their partners as well as manage their personal experiences. Specific benefits reported included gaining increased information about the disease, a

higher level of hope, and being able to connect with women in a similar situation. The authors suggest that women's involvement in such support groups is to be encouraged, in order to enhance their effectiveness for both men and women.

My thesis builds upon this research, developing the gendered element to health research as there is a focus on support groups and gender in cancer research, but also empirically as the thesis investigates an under-researched area. The work of Bottorff et al investigated the experiences of women in a prostate cancer support group – women cannot be diagnosed with prostate cancer so these women were there purely in a supportive role. My research builds on this, similarly focusing on the experiences of a demographic of people one would not expect to utilise a specific cancer support group, but developing this further as men *can* be diagnosed with breast cancer. By looking at the experiences of a minority group within the context of a majority group, this thesis has developed from previous research and supports the findings that one does not need to be part of the perceived majority group in order to benefit from what support groups have to offer their users.

The findings from my thesis offer new insights into an under-researched area. Breast cancer as a whole is a well-researched area; for example Bell (2014) researched the impact of discourses surrounding breast cancer on people who had been diagnosed with a different form of cancer. Breast cancer has prominence in the Western world and arguably this prominence is more important than its prevalence. In line with this, many organisations choose to support breast cancer awareness, for example through the production of 'pink ribbon' items, as this can be seen to enhance the corporate image. Bell used a discourse analysis approach for her qualitative semi-structured interviews, the same approach my research took. Both my research and Bell's examine the dominance of breast cancer, but from different focal points: hers focuses on the experiences of people diagnosed with another form of the illness, and mine focuses on the experiences of a minority group. My thesis also explores the potential negative impacts of the pink ribbon and its associated culture. As Bell showed, there are negative stigmas, often incorrect, associated with other cancers such as lung cancer and smoking, cervical cancer and sexual promiscuity, whereas breast

cancer does not have a negative image; the emphasis is more on innocence, purity and virtue. Bell argues that historically the health needs of women have been neglected compared with those of men, which in part justifies the focus on women's health currently, and breast cancer specifically. However, my research positions itself in such a way that it builds on this, to highlight the requirements and experiences of men within this patient group, and as such contributes to an under-researched area.

Participants in Bell's study used breast cancer as a lens through which to understand their experiences of cancer and the effects of their disease. Some participants saw their experiences as less invasive or less traumatic than those of a woman with breast cancer (for example, a small surgical scar compared with a mastectomy). Breast cancer is clearly an important disease to continue to study as there are potentially wide-ranging implications of research findings. In particular, researchers need to be aware of this phenomenon named by Bell as 'breast-cancer-ization' and its potential effects in terms of people's experiences of cancer, as well as how willing they are to participate in research generally.

Macdonald, Watt and Macleod (2013) found from their research with people who do not have cancer that discussions around cancer tend to be quite negative, such as connotations of intensive treatments with an array of negative side effects, as well as general uncertainty about the future. Whilst there is an acknowledgement of improvements in outcomes, there is also a certain amount of unpredictability. This research pinpoints negative ideas about cancer held by members of the general population and shows people are already concerned about the effects of a cancer diagnosis before they are ever diagnosed with the disease. As such, it is important to conduct research into the experiences of people with cancer to create more knowledge and perhaps lessen fear. Research into rare cancers and uncommon diagnoses (such as breast cancer in men) could generate more knowledge into areas where information is significantly lacking. This has the potential to benefit both those diagnosed with the disease themselves, as well as provide information to the general public.

Perceptions about breast cancer were also researched by Silk et al (2006) who conducted focus groups with adolescent and adult females (none of

whom had breast cancer) in which the participants were asked what they thought about breast cancer, for example its severity and their susceptibility. There is a need to understand the public's understanding of breast cancer in order to deliver suitable and effective public health campaigns. Younger people especially need to be educated about their risks so they can develop appropriate behaviours such as regular exercise and not smoking. The study showed that many adolescents in the focus groups were unsure as to whether men could be diagnosed with breast cancer. This shows that there needs to be more work conducted in this area; both young women and men need to be aware of the risks surrounding breast cancer and be accurately informed where people about individuals' susceptibility. The findings of my thesis showed many adults are unaware that men too can be diagnosed with breast cancer, which in part led to men being diagnosed at a later stage, as well as people being unsure about their involvement in cancer support groups. Future research can build upon this, to increase accurate awareness about breast cancer as a whole, and not just position it as a disease of women.

So far, it has been discussed how my thesis contributes to, and extends current work, both in considering a gendered element to health research and empirically, by offering something new in an under-researched area. It also builds upon research through the methods utilised. Seale, Ziebland and Charteris-Black (2006) examined language in interviews and online support groups, finding clear differences between men and women. Men used the internet to get information, whereas women used it predominantly for support. Men focused on specific information, such as treatment for specific parts of the body, whereas women were more holistic. Internet forums are public, and yet seen by both men and women as places for exchanging quite personal information. My own research builds on previous research on internet forums, again demonstrating how they are an excellent site for conducting sociological research, a site which has the potential to be used to greater effect in the future.

Implications for future research

Whilst this thesis is based upon data from three datasets, to broaden these datasets would be beneficial in terms of extending the ideas of marginality

raised in this thesis. The datasets comprising of the newspaper articles and the forums were international in focus, but the interview dataset consisted of interviews with people who were all based in the United Kingdom (and all, except one, were British). The number of men diagnosed with breast cancer each year is small, and the number willing to participate in research smaller still, but to be able to interview individuals of other nationalities, living in other countries, would be beneficial in terms of enabling the further exploration of the relevance of marginality, and how men experience being a breast cancer patient, as well as showing the mechanisms through which they are currently less able to participate within this breast cancer community.

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